

## The Wider Impact

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The stories of SARS victims, their families and friends are as plentiful as they are painful and are told in detail in this report. There were other victims who did not contract the disease but who nonetheless suffered from its spin-off effects. These are the hidden SARS victims, those who suffered stress and emotional pain resulting from disruptions in health care, and from the systemic lack of preparation, policies and simple systems to encourage consistent and fair handling of those who needed access to their sick relatives. These systemic failures resulted in great stress and anxiety.

Many hidden victims were members of vulnerable populations: the elderly, the physically and mentally impaired, and those who could not speak English. They had difficulty navigating through a health care environment that is complicated at the best of times but was especially confusing and frightening during SARS. Hidden victims were those who stood by as people close to them died alone because of visiting restrictions. They were people forbidden from accompanying a relative or friend to medical assessments or treatments. In some cases they were people who needed treatments but had to wait because SARS had turned the system upside down.

It is easy now to forget just how disrupted and confused the health care system was during the SARS outbreak. This was a new disease, and the system was unsure how it was spread, how it might be controlled and, in fact, whether it could be controlled completely. It was highly infectious and deadly and it seemed reasonable at the time that health care facilities and their staff do whatever was needed to stop it.

Most people understood the seriousness of SARS and the need for precautions at hospitals and other health care facilities. Many of the hidden victims felt, however, that the health care system was too rigid, cold and uncaring to people struggling with life and death issues. The daughter of a cancer patient, noting a no-visitor policy at a cancer treatment hospital, put it this way:

I know that this was all for safety precautions. I understand all that but you know when someone in your family is all alone there, then you feel angry at a certain point. You would wait outside and you don't know what he's doing in there.

There were many stories of people being handled with less sensitivity than might be expected. However, in these cases it wasn't simply health care staff being uncaring or mean. Systemic failures, not individual care facilities or staff, are behind what went wrong in the stories of the hidden victims. Lurking in the background of each case are signs of lack of preparedness, lack of policies and lack of simple administrative machinery that could have helped to avoid these horror stories.

The lessons from these stories are: Be better prepared for infectious outbreaks, build better systems to handle effectively all aspects of the crisis, be clear about who is in charge, and above all, communicate regularly and clearly with those affected.

Here are some of the hidden victim stories as told to the Commission.

## **A Case of Inconsistent Rules**

Ms. K recalled how her elderly father became a bystander victim in the management of SARS. He was a patient at a Toronto hospital where he spent five weeks isolated from his family because of visiting restrictions introduced to curb the potential spread of SARS. He was paralyzed from the neck down with ALS, Lou Gehrig's disease. His physician refused the family visiting rights on the basis of hospital policy. The family tried to appeal the no-visitor decision. They called the hospital CEO and its Chief Medical Officer but did not hear back from either. They tried contacting Dr. Colin D'Cunha, Ontario's Chief Medical Officer of Health, and Dr. Sheela Basrur, the Toronto Medical Officer of Health. These offices referred them back to the father's physician, who had refused visiting permission in the first place. Ms. K said:

I was at the end of my tether. Nobody had explained to us why we couldn't see my father. It was like living in a pressure cooker. I could not

believe I was still living in Canada. It seemed as if [the hospital] and its physicians had become a law unto itself.<sup>819</sup>

The daughter turned to the media for help. She emailed the *Toronto Star* begging for assistance. A reporter called the hospital community relations department and on May 5 the patient's wife received permission to see her husband. She had not seen him for 40 days. He died two weeks later.

As Ms. K told the Commission:

I should not have had to depend on the media call to see my father. My own call should have been enough.<sup>820</sup>

She said her mother still is unable to handle the fact of not having been with her husband in the final weeks before his death:

She is still traumatized that she could not fulfill her cultural and religious obligations to the full.

She is haunted by the memories of those five weeks and what she saw as the cold indifference of physicians in power. She says this cruelty must never happen again.<sup>821</sup>

What was missing was a system through which families who felt unfairly dealt with could appeal to a senior hospital official or team of senior staff. Different health care staff had different views about access or visiting during SARS. Patients and their families should have had recourse to review such decisions without going to the news media.

## The Man Who Died Alone

Similarly, a 96-year-old man who had been living with his disabled grandson was taken to a hospital in the Greater Toronto Area, where he was diagnosed as requiring chronic care. The man's daughter and his grandson visited regularly but one day

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819. SARS Commission Public Hearings, November 17, 2003.

820. SARS Commission Public Hearings, November 17, 2003.

821. SARS Commission Public Hearings, November 17, 2003.

arrived to find the hospital closed because of SARS. The elderly man's condition was classified as chronic, but not critical; still he was not permitted visitors. The daughter tried unsuccessfully to have her dad's condition changed to critical from chronic so visits could resume; however, calls to the attending physician and the man's family doctor were not returned. The hospital said that when the man's condition became grave they would call her and she could visit just before he died. The only call she received was that her father had passed away.

## **Fifteen Minutes Too Late**

One man told of trying to visit his 56-year-old mother at hospital outside the Toronto area. She was admitted just after Mother's Day, right at the height of the spring 2003 outbreak. She needed surgery on some toes affected by diabetes and he went to visit her before the operation. He told the Commission he was physically removed from the hospital by security staff despite his understanding that his mother had placed his name on a list of visitors and that this was all that was required to secure a visit.

Later he received a call from a nurse saying he should come to the hospital because his mother had had a heart attack. When he arrived he was allowed to go to the intensive care unit without any SARS screening. He talked with a doctor who said he was 15 minutes too late. His mother had passed away.

He described himself as "emotionally wrecked."

This is one more example of the misunderstandings that can lead so easily to a tragic sense of loss when there is no preparedness and no systems to ensure reasonable policies and sensitive communications.

## **High Anxiety and Nightmares**

Enforced separations also created anxiety and pain for people in long-term chronic care facilities and their families. One woman told the Commission how she could not visit and care for her disabled mother for 29 days during the SARS crisis. The facility did not have any SARS cases but imposed visitor bans as a precaution. The mother had suffered a serious brain injury more than two decades earlier. She had been in long-term care since, receiving almost daily care from the daughter:

I promised her that I would remain at her side for as long as she needed me ... I have managed to be at her bedside every day or second day for the last 21 years. I am there to give my mother her personal care, to feed her, to assess her health and to advocate on her behalf.

The visitor bans caused her mother much distress because “I could not prepare her for the sight of staff in their space suits hidden behind their visors, goggles, masks, gowns and gloves.” The daughter said:

My mother will never be able to tell me what her experience was of those 29 days. For me there was high anxiety, nightmares.

The daughter told the Commission that she watched with interest as the Hospital for Sick Children<sup>822</sup> allowed one family member to be with each patient during SARS. A parent was allowed to be with a sick kid, but adult children were not allowed to be with their parent at this long-term care facility:

I and others feel that we are the parent and our loved ones the child, regardless of our blood relationship.

The daughter also said that the facility used the SARS experience to impose what she called greatly altered, reduced and awkward split visiting hours.

She said:

The administration has, by their actions, said that we were not needed during the crisis and that we are needed even less now, post-SARS. Of course, if our loved ones could, they would tell them differently. To me it feels like a hijacking. A hijacking of mine and my mother’s rights or as if Big Brother has come along and taken over and only when Big Brother says I can will I see my dear mother.

She said long-term care facilities should distinguish between visitors and hands-on family caregivers when deciding visiting hours.

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822. The Commission is not saying or suggesting that the Hospital for Sick Children did anything wrong. They were following the directives and allowing parents to accompany ill children, as the directives permitted. The point is not that they did anything wrong, but that consideration ought to have been given for the needs of elderly patients.

This woman's criticism of her mother's long-term care facility is understandable. So are the restrictions placed by the home, when seen from an infection control perspective. The key is that these facilities should work with families so that policies blend the need for infection control and the needs of patients and their families. There is need here for discussion and explanation, not simply arbitrary restrictions. Perhaps there is something in the Hospital for Sick Children's approach that could be applied to other facilities.

## Impact on the Elderly

Another woman told of how her family suffered trauma when access to her father was denied at both a hospital and his long-term care home. The 81-year-old father lived in a long-term care facility where visiting was restricted then cancelled because of SARS. She said:

This had a devastating impact on all seniors, both emotionally as well as physically. They might as well have been in prison. Tuck shops were closed. All activities run by the volunteers were suspended.

The father was suffering foot infections related to diabetes and was admitted to hospital. Doctors decided that his legs must be amputated. The day of the scheduled surgery the daughter arrived at the hospital and was denied entrance. The hospital had been closed to visitors because of SARS. She and her sister sat from 6:30 a.m. to 4:00 p.m. in the space between two sets of doors at the hospital main entrance. The father suffered amputations that were more extensive than planned without seeing his family before surgery or after. Both legs were removed at mid-thigh.

He returned to his long-term care home, where he coped but had trouble sitting in a wheelchair without legs as a counterbalance. He developed an infected bedsore. He was admitted to hospital again, this time another one, which was closed because of SARS a few days after he arrived. He was discharged after eight days, but he and his family were put into quarantine because of their connection with the hospital, which had active SARS patients. He had to cope without family help, and when his daughter telephoned a nurse to ask her to look in on him, she was told:

We are trying to go into his room as little as possible as we are afraid of catching something and spreading it to the other residents.

The daughter told the nurse the quarantine was only a precaution and nurses at the home had been issued protective equipment in the form of masks, gowns and gloves.

The father died unexpectedly on June 22. His daughter said that the next time hospitals are shut down by a medical emergency, seniors should be given the same considerations as children:

Seniors are much like children. Any change in routine causes extreme anxiety, stress and confusion. Seniors need to be able to have someone there with them during peak times of 7:30 a.m. and 9:00 p.m. Someone to speak for them when needed, to help understand medical diagnosis and treatment, and to help with medical histories. Someone to help them with the simplest task like raising or lowering their bed, with their meals, their personal hygiene and to reassure them, just to be there with them. These are all the things a family member would have been doing for them. To deny seniors this basic right is simply wrong.

Another case involving the elderly shows how SARS impacted the quality of life of many older citizens who came into contact with it. One gentleman went into hospital for a hip operation, contracted SARS, and infected his wife. Rehabilitation exercises are critical in recovering from hip surgery, but he could not complete his rehabilitation program because of SARS. Now he has difficulty walking.

The family was interviewed by the Commission. His daughter described what happened:

When you have a hip replacement, you've got to be up the next day. Well, he was. I remember the phone call after the hip replacement because he was about four days with therapy. He was so excited that he could walk so much better now, and I remember they were making him do the stairs and he was so happy. And then he got taken with SARS to another hospital and that was it for the therapy. For five weeks he lay in the bed with no therapy.

No therapist would go in with nobody knowing anything about SARS, nobody would even go in the room except the doctor. And even though he was well after one week, they wouldn't take him out of isolation because, well, they would release him to me but I'm untrained. But even if he went home, I tried two different nursing companies, private nurses, nursing companies and the second I said he's going to be in quarantine from SARS, that was it. They said no.

So I said to the hospital, if trained professionals won't come in because they don't know anything about SARS, I certainly am not a medical professional and able to protect myself or my daughter for him to come into my home or my brother's home. You know, they have children. And they said that's our only option. And it was a big fight with administration.

The daughter enlisted her MPP to get her father released to another facility, where he finished his quarantine in a private room. But it was too late for rehab.

The system, unprepared, could not cope with this man's pressing medical need. A system better prepared is required to prevent this kind of medical damage.

## Shifting Policies and Practices

The Commission heard much about the lack of consistency and clarity of rules and restrictions put into place during SARS. A woman told the Commission her family's story of trying to navigate conflicting hospital policies and practices. On March 27, 2003, her father was in such pain from cancer that his wife and son brought him to a hospital in Greater Toronto Area. Only his wife was allowed to accompany him into the emergency department.

The next day, the wife went to visit him but was told by a nurse that visits were not allowed because of SARS. Later, the hospital said they would allow one visitor for one hour per day. Then they said someone would have to telephone ahead and provide the name of the visitor.

Said the daughter:

And so it went. Each day the rules seemed to change with respect to visitors. Not only with respect to the number of visitors but also when it came to washing our hands, having our temperatures taken or completing the sign-in sheet on the door where my father was staying. Sometimes these tasks were monitored and other times they seemed to be forgotten. It also seemed that some staff members seemed to enforce the rules more than others.

Four days after the man's admittance, the family was told that patient visits were suspended. The family called the hospital ombudsman, their MPP and some other



public officials. On April 1, the hospital said it would allow one visitor a day if the name was provided in advance. This policy created a problem when the man's 91-year-old mother wanted to visit. She was blind and hearing impaired and needed someone in the family to escort her through the hospital. The hospital at first allowed this, then changed its mind. The elderly woman had to find her way own way to her dying son's room. Later the man asked to be discharged so he could die at home.

His daughter told the Commission:

I truly believe that the quality of my father's life during his final days was affected by being kept isolated from his family. He needed our support and we were not allowed to be with him.

What difference would it have made if there was more than one visitor at a time? Or if the visitor stayed for more than one hour per day? Would that really put the hospital at greater risk? I don't think the health care administrators thought about the impact of those restrictions on patients in palliative care. Patients who had nothing left to hang on for, except seeing their loved ones.

Once again it is hard to fault the individual hospital and its staff. They were forced to make up visiting policies as they went along. The health system must understand the vital human importance of visits to the sick. Advance planning is needed to create systems and policies to ensure a safe, humane and sensitive health system during infectious outbreaks.

## Hospitals Under Stress

Another woman's story illustrates the tension among hospital staff during SARS and how it reduced quality of care for patients who did not contract SARS. Her story is another example of the tremendous stress under which hospital staff, from doctors and nurses to cleaners and security staff, had to labour.

She told of how her father was in a Toronto-area hospital for hernia surgery in May 2003. The man was 85 years old and did not do well after the surgery, and his stay was extended. At first the family was allowed to visit frequently, then two SARS patients were brought to the hospital and visits were limited to one person at a time for five minutes:

This [admission of SARS patients] seemed to put the fear of death into the staff. Nurses didn't want to discuss the fact that two SARS patients were in their unit.

The father died in that hospital during the second week of June. Visiting was restricted when he died. His son and a granddaughter who had travelled from overseas were not allowed in to see him before he passed away. The daughter said:

For the last 17 days of Dad's life he never felt human contact. For a man who always reached for someone's hand to hold, whether it was his daughter's or one of his 10 grandchildren, all he got was a latex glove. The grandchildren are left with this awful image of not being allowed to be with their precious grandfather for the last week of his life.

The coroner's office ordered an autopsy. The daughter told the Commission that five months after the autopsy they still did not have the results, although they had been told he did not die of SARS:

We still don't have closure. A lifetime of love and caring that ended with neglect and loneliness.

## **Quarantine: Confusion, Controversy and Hardships**

There had been no widespread use of quarantine in Ontario for 50 years, so it is not surprising that quarantine during SARS caused confusion, controversy and stress. By one official estimate, 15,000 to 20,000 Ontarians entered quarantine during the outbreak.<sup>823</sup> But there is some confusion about how many people were under home quarantine, how many under work quarantine, how many were actually contacted by public health and how many quarantined themselves voluntarily without ever speaking to public health authorities.

It is likely that somewhere around 30,000 people observed quarantine during the outbreak in Ontario. Virtually all of those entered quarantine voluntarily. Sixty-five persons were issued Section 22 orders during SARS; one was served with a Section 35 order, and the latter was a matter of some controversy. Section 22 of Ontario's *Health Protection and Promotion Act* allows a medical officer of health to require a person to

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823. SARS Commission Public Hearings, September 29, 2003.

take (or refrain from taking) any action specified in the order regarding a communicable disease. Action under the order can include directing a person to remain at home while a danger to others. Section 35, used for people who refuse to comply, allows the Ontario Court of Justice to issue an order directing compliance, and may also require police to help to enforce it by taking the person into custody and admitting the person involuntarily to hospital.

The glaring inadequacy of Ontario's antiquated *Health Protection and Promotion Act* is described in the Commission's Second Interim Report.<sup>824</sup>

The term "quarantine" is often misconstrued, and sometimes confused with isolation. Both are defences during infectious disease outbreaks. Public health officials must have the power to isolate those who are infected, and to quarantine those who might have been exposed to infection and might be infectious to others. The U.S. Centers for Disease Control and Prevention defines both:

Isolation refers to the separation of persons who have a specific infectious illness from those who are healthy and the restriction of their movement to stop the spread of that illness. Isolation allows for the focused delivery of specialized health care to people who are ill, and it protects healthy people from getting sick. People in isolation may be cared for in their homes, in hospitals, or in designated healthcare facilities.

Quarantine refers to the separation and restriction of movement of persons who, while not yet ill, have been exposed to an infectious agent and therefore may become infectious. Quarantine of exposed persons is a public health strategy, like isolation, that is intended to stop the spread of infectious disease.<sup>825</sup>

Ontario was not the only jurisdiction to use quarantine during the 2003 outbreak period. China, Taiwan, Singapore and Hong Kong were the main areas of Asia affected by SARS and they also responded with quarantine. However, the approaches to quarantine in Asia and Ontario were quite different. Some Asian jurisdictions set up police checkpoints, cordoned off entire villages, and even threatened to execute anyone who broke quarantine.<sup>826</sup> In Ontario, public authorities used voluntary quar-

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824. For more analysis of the legislation and the problems that arose during SARS, see the SARS Commission, second interim report.

825. CDC *Isolation and Quarantine (SARS)*, [www.cdc.gov/ncidod/sars/isolationquarantine.htm](http://www.cdc.gov/ncidod/sars/isolationquarantine.htm).

826. Article by Brian Friel, National Journal Group Inc, October 21, 2005.

antine and in some cases provided food and supplies needed during isolation.

Ontario's quarantine involved staying at home for 10 days, after which the risk of having been infected was considered over. Quarantined individuals slept separately from other people in the home, wore masks when near others and were not to share personal items.

Toronto used work quarantine for health workers exposed to SARS but who remained healthy. These health workers continued at their jobs but stayed in home quarantine after working hours. They were expected to travel to work in isolation (i.e., not using public transit) and were asked to closely monitor themselves for signs and symptoms of SARS, including twice daily temperature checks. The idea of work quarantine was to ensure that there were enough health care workers available. If every health worker exposed to SARS had to remain in home quarantine, there would have been a tremendous, and perhaps impossible, strain on health facilities because of worker shortages.

Quarantine was discussed in the Commission's interim reports. The purpose of raising it here is to illustrate how quarantine disrupted the working and home lives of thousands of Ontarians who suffered considerable emotional and psychological strain because of SARS.

Public hearings and private interviews produced many individual stories of the hardships and stress caused by quarantine. People told the Commission of the stress of being isolated from family and friends, plus the anxiety they developed from fear that they might have SARS and pass it on to their children or other family members.

The Ontario Nurses' Association presented this collage of quotations from nurses who were quarantined because of possible contact with SARS at work:

Quarantine was very difficult. Not being near my family, not being able to touch them.

I was sleepless, stressed, feeling despair every time I went to work. I felt depressed, angry at how it was mishandled, especially isolated, suffered from insomnia and had a tremendous fear of bringing a deadly disease home to my children. The babysitter refused to babysit my child. Friends, family and parents of my child's classmates did not want their kids to play or contact my family.

I had several vivid nightmares during outbreaks that my children were ill with SARS. One night I woke and ran to the bed of my youngest who was clutching her forehead, convinced she was burning with a high fever. My youngest child was teased and isolated by her peers because her mother was a nurse at a SARS hospital.

My husband and children moved out for 12 days. Grandparents changed schedules to care for the children. There was stigma from friends outside of work. I suffered nightmares.

I was very much isolated from loved ones. My family thought I was going to die.

Just last week a number of ONA members who developed SARS after caring for SARS patients told me they continue to suffer severe emotional and physical repercussions of a disease that we still don't know that much about.<sup>827</sup>

Roughly 7,000 persons were sent into home or work quarantine because they had a connection to North York General Hospital, the epicentre of the SARS II outbreak. Some 4,000 were hospital staff. Bonnie Adamson, president and CEO of the hospital, told the public hearings of the tremendous hardships caused by quarantine:

For many of them the situation made them feel like pariahs in their own community. We heard reports of neighbours crossing the street to avoid houses where our staff lived and even an eviction notice to one of our staff members by nervous roommates ... Many were unable to attend important family milestones: weddings, graduations and even the funeral of parents, and these are events that could never, ever come back.<sup>828</sup>

Many of the stories of hardships during quarantine are anecdotal. However, hard evidence of the effects is found in a study by researchers in Toronto and New York. It found that of 129 quarantined persons studied, 28.9 per cent showed symptoms of

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827. SARS Commission Public Hearings, September 29, 2003.

828. SARS Commission Public Hearings, September 30, 2003.

post-traumatic stress disorder (PTSD). Symptoms of depression were observed in 31.2 per cent.<sup>829</sup>

All respondents described a sense of isolation. The mandated lack of social and, especially, the lack of any physical contact with family members were identified as particularly difficult. Confinement within the home or between work and home, not being able to see friends, not being able to shop for basic necessities of everyday life, and not being able to purchase thermometers and prescribed medications enhanced their feeling of distance from the outside world. Infection control measures imposed not only the physical discomfort of having to wear a mask but also significantly contributed to the sense of isolation.

This study said that just making temperature checks caused anxiety in some people. It quoted two people as illustrations:

Taking temperatures was mentally difficult, said one.

Said another:

Taking my temperature made my heart feel like it was going to pound out of my chest each time.

Following quarantine, 51 per cent of respondents had experiences that made them feel that people were reacting differently to them: avoiding them, 29 per cent; not calling them, 8 per cent; not inviting them to events, 8 per cent; and not inviting their families to events, 8 per cent.<sup>830</sup>

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829. Laura Hawryluk et al., "SARS Control and Psychological Effects of Quarantine", *Emerging Infectious Diseases*, Vol. 10, No. 7, July 2004 (Hawryluk et al., "SARS Control and Psychological Effects of Quarantine")

830. Hawryluk et al, "SARS Control and Psychological Effects of Quarantine".

### *Individual Stories*

One of the most serious effects of quarantine was that it kept people apart when they needed to be near family and friends. In so many cases, a family member was ill, or dying of SARS, and those close to him or her were unable to provide normal care and comfort to the patient or each other.

Said one man who lost both parents to SARS:

Nobody could see each other. Finally I was able to get permission to go visit Mom because she was dying but I couldn't go next door to visit my sister or two doors down to visit the girls [his nieces].

When a death did occur, some people were not able to pay their last respects or attend funeral services because they were under quarantine. More is said about this under the section on funerals.

Quarantine affected many people who had no risk of exposure to SARS until they had to visit a medical facility for treatment of an existing condition, or for examination and tests. A kidney dialysis patient told of how he had to take treatment three times a week at a hospital. He complained about confusion over SARS quarantine. After one treatment, public health authorities called him and said he must be in quarantine, which included wearing a mask at home and not sleeping with his wife. Other dialysis patients told him they were not quarantined. However, every time he went for dialysis he was placed under a new ten-day quarantine. He complained to public health that he could be in quarantine for the rest of his life and maintained that only people sick with SARS should have been quarantined.

Shunning of people possibly exposed to SARS in some cases continued after a person ended the quarantine period and was symptom free. One woman told of how her adult son gave up a business connection, partly because the people with whom he worked found out he had been in quarantine:

... when this happened [quarantine] he had to stay home and he chose not to tell the other people in the office why he was home because people were very skeptical about being around people and whatever. When his time was finished with the isolation [quarantine] he did tell them why he had been off and things didn't go very well. They almost threw him out and said how could you do that when there was other people at risk who

had families that he worked with and it just got worse and worse ... I'm not saying that this was a whole result of this but this was kind of the icing on the cake ... they were very irate.

One woman whose family suffered three SARS deaths told of the effects on her children. Their father was in hospital desperately ill with SARS and they were quarantined at home:

My daughter missed her play, the school play that they've been working on all year, and I couldn't get the school to put it off for a week. She missed it. My kids were just so isolated and the school wasn't doing anything, and they were sending homework home. That's what they were doing, they were sending homework and leaving it on the porch.

To help ease the strain and break the boredom, the mother called friends and asked them to bring children over to hold signs, sing and perform skits while the quarantined kids watched from inside:

And they did and it made such a difference. I was so angry that my children's mental health was left to me. Like, where are all, where's public health, where are the schools, where's the school boards, you've got mental health issues going on here in quarantined homes, and nothing, nothing in the system.

The problems did not end when quarantine did. A daughter was not allowed to return to her high school after quarantine. She missed her Grade 11 final exams and was penalized 30 per cent of her marks for not being able to take the exams. Her mother said:

That's what my daughter's dealing with now. So, in Grade 12, she has to maintain an average over and above, aside from the fact that they didn't make up the materials she missed, they kept her out of school for a fair bit of that last term.

The schools didn't know how to respond or react, they had parents panicking ... The absurdity became that my kids, although not in quarantine, weren't in school, they were at the mall, because they weren't quarantined anymore ...



Another woman had to get public health to help her fight a principal who banned her daughter from school. No one in the family was ill or quarantined but the principal had heard that the woman's mother worked at an infected hospital. She said:

I knew the principal quite well at the school and he tried to ban my child going to school and then again I had to phone public health and she ... phoned over to the school and also faxed a letter to him that he could not do that.

Some schools were closed and students and staff ordered into home quarantine when officials feared students had been exposed to SARS. Quarantine affected 1,700 students at one school in the Greater Toronto Area.

One student told the media he was upset because he missed his girlfriend's prom night because he was in quarantine:

It's so hard for me right now, because I'm 19 years old, and whenever I'm not in school, I'm out. So for me to be stuck in my house is the hardest thing.

Mixed in with all the stories of hardships caused by quarantine were some stories of human kindness. Like the friends who gathered outside the home of the quarantined kids to perform skits, and the people who assembled outside a hospital to cheer on the work-quarantined staff.

Toronto Emergency Medical Services told this story to the public hearings:

We got a phone call from someone who said "my nine-year-old son's birthday is Friday. My whole family is in quarantine. Can someone please go buy a birthday present for my son?" And we took care of that ...<sup>831</sup>

This last story is so typical of those health workers who went the extra mile to help the sick. The story of SARS quarantine, with all its problems, is the story of magnificent work by health workers and magnificent voluntary support from the public. As noted in the Commission's interim reports, systems are required to support and encourage this magnificent cooperation by health workers and the public.

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831. SARS Commission Public Hearings, September 29, 2003.

## No Chance to Provide Support

One woman told of the difficulties of not being with her companion when he went for cancer treatments. On April 8, 2003, she took him to a cancer clinic. She was not allowed to enter the hospital and sat between the double doors at the entrance while he sat in the waiting room for three hours. Another time he had a doctor's appointment and the results were expected to be grim, but she was not allowed in to give him support. In May he was very sick and she took him to hospital, where she was told she would have to wait in the car. She went home and eight hours later the hospital called and told her to come and pick up her companion. The man succumbed to his cancer not long after.

## Critical Treatment Delays

One doctor told the Commission of a study her hospital did of cancer patients requiring treatment during SARS. The study showed that when SARS screening measures were first introduced, there was confusion because "we didn't know what we were doing":

We were dealing with sobbing patients, husbands threatening to bomb us because we wouldn't allow them in with their wives [newly diagnosed with cancer].

The doctor said directives relating to SARS were so frequent that information didn't get passed along in a timely fashion to staff and patients. One man was told he could bring his wife when he came for his treatment. When they got there she was turned away and had to wait in the car. Another man diagnosed with cancer was scheduled for treatment as SARS began. The treatment was delayed three months and of course he was distressed because the delay could give the cancer more time to spread.

SARS made hospital visits especially difficult for new patients. They were already traumatized by recent cancer diagnosis and were confused and even frightened by hospital systems and routine.

Said one patient:

For me my experience is so scary because the first day you come to hospital you know the diagnosis was cancer and there was no visitor with me.

That is something missing, the support. When I step into the hospital and I just get crying.

Said another whose husband had a brain tumour:

There is no reason a spouse can't be with them. He was unable to go anywhere without me. I could not leave him at all so why can't I come? There's no difference in SARS exposure information for either of us.

Her point is understandable considering that some brain injury patients are unable to record properly what doctors are telling them. Some are unable to take notes, like many patients do. Even patients without any brain impairment have difficulty absorbing and accurately recording what health care professionals tell them about diagnosis and treatment.

What is required is a system that plans ahead to minimize as much as possible the collateral impact of infectious outbreaks on necessary medical treatments.

## Common Threads

A common thread in all these stories is the lack of someone to turn to for appeal. Most of these hidden victims could have found comfort in being able to approach one person at a hospital or other care facility who could have provided facts and explanations, and even overturned any access decisions that might have been made in the heat of battle. SARS was confusing and health workers under extreme stress made judgment calls that they thought best. In the absence of preparedness and consistent policies, they were often forced to make it up as they went along. For the hidden victims there was no one to turn to for explanation or discussion of those judgment calls. No person should have had to turn to the daily newspaper to gain access to a dying relative, as did the woman in the first story related above.

These stories also show what was seen in other aspects of the SARS outbreak: not being prepared. The health system needed simple policies and practices to meet the needs of not only victims, but family and friends and other innocent bystanders. Bad things always happen in times of crisis. That is part of life. However, policies thought out in advance, strengthened through staff training and applied consistently, would have prevented at least some of the grief suffered by these hidden victims.

## Impact on the Chinese and Southeast Asian Communities

No ethnic group was more affected by the SARS outbreak than Toronto's 400,000-strong Canadian Chinese and Southeast Asian community. It was widely reported that the outbreak originated in Asia. The stigma was immediate, especially in those parts of the Greater Toronto Area where Chinese and other Asian restaurants and businesses are concentrated.

Citizens and tourists avoided people of Chinese background for fear that they carried the new disease. They avoided them on the streets, at work and at their places of business. Normally jammed with customers, these areas were deserted. Not only did tourists and restaurant customers stay away, but the Chinese Canadian residents stayed home as well.

The Chinese-Canadian National Council (CCNC) estimated the loss of income to businesses in the "Chinatown" areas at 40 per cent to 80 per cent, depending on the type and location of the business. The loss was substantially worse than that suffered generally by businesses across Toronto.

Politicians and public officials took notice of Chinatown's plight. Prime Minister Jean Chrétien and Ontario's Lieutenant Governor James K. Bartleman made photo-op dining visits to Chinese restaurants. Some Chinese Canadians said these gestures did not make a big difference, but others applauded the intervention.

The impact of SARS on individual Chinese and Southeast Asians Canadians went beyond business loss. Many service workers, including live-in caregivers and restaurant waiters, lost their jobs.

Members of the Chinese and Southeast Asian communities felt they were stigmatized unfairly, and were wrongly blamed for the emergence of SARS. They felt racism was at play. The Chinese-Canadian National Council's report blames the media, which always raises the spectre of the "shoot the messenger" exercise. But the problem was widely recognized and as noted earlier, public health stressed to the public that it was not easy to contract SARS and that race had nothing to do with getting it.<sup>832</sup>

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832. SARS news conference, April 5, 2003.

Chinese Canadians noted that people moved away from them on subway trains and their children were sometimes shunned at school.

Hospitality workers felt the effects most directly. When customers avoided Chinese restaurants, waiters were sent home. Live-in caregivers caring for children and the elderly were especially vulnerable. About 70 to 80 per cent of them come from the Philippines under a government program. SARS had a great impact on their lives since, unlike health professionals, they have few guaranteed rights and little job protection.

Coco Diaz of Intercede, an organization for the live-ins, told the CCNC researchers:

There were many cases of unfair termination of employment during SARS. They were dismissed as if they were already carriers of the disease. Employers were most concerned with the elderly or children in the family and yet showed little concern for their employees.

She told of a live-in who contracted SARS by taking the elderly person in her care to the hospital. The live-in spent three months in a coma and had to undergo many months of rehabilitation.

Ms. Diaz reported that unfair dismissals intensified in April 2003 when the media reported the links of several new SARS cases to members of a Filipino Catholic group:

Immediately, some employers started to think that just because the workers are Filipino, then no, they cannot come and work.

Some who employed live-ins worried that their employees would get exposed to SARS during their days off and bring it back to the household. In some cases, live-in employees were quarantined for 10 days after returning from their days off, then were dismissed anyway when the quarantine ended.

To a live-in caregiver, the loss of a job also means the loss of a home, since they usually live with their employers. To lose a job is to jeopardize immigration status.

The Metro Toronto Chinese and Southeast Asian Legal Clinic told the Commission's public hearings that, ironically, Chinese and Filipino Canadians were the ones who fought on the front line as nurses, doctors, and other health care workers. Nursing is one of the few professions where Asians, particularly people of Chinese and Filipino descent, are well represented, the clinic said:

So while Asian Canadians on the street were being targeted, Asian Canadian health care workers were risking their lives for the people who were inflicted, inflicted with the disease. It is not a coincidence that the two nurses and the doctor who died from SARS, were persons of either Chinese or Filipino descent.<sup>833</sup>

The clinic noted that anti-Chinese sentiment has always been present in Canada, notably when Chinese labourers were brought to Canada to build the early railways. When the SARS outbreak occurred and was reported to have originated from Asia, racism based on fear of Chinese carrying the disease emerged again:

Images of Chinese Canadians wearing masks began to appear in mainstream media reports and this new fear the Chinese Canadian Community, while never spoken was certainly felt by members of the Canadian public ... It was also around that time that our clinic began to receive calls from individuals who became the casualty of SARS, although not in the medical sense.

While some workers lost their jobs in restaurants and other workplaces from the economic impact of SARS, others reported discrimination based on the idea that SARS was a Chinese or Asian illness:

We received a number of complaints from tenants who got kicked out by their landlord because they were Chinese. Some of them were new immigrants or recent immigrants from China but one of these tenants who called us was, in fact, a Canadian-born Chinese who had never set foot in China or in Hong Kong and who actually lived in Guelph outside of the epidemic centre of SARS. She was told by her landlord to move out ...

The clinic also heard from many workers of Chinese descent who were terminated or told to say home because of perceived fear from their non-Chinese colleagues:

There was a nursing home which served primarily Chinese Canadian seniors where some nurses refused to work because of a totally unfounded rumour that the nursing home residents had contacted SARS.

Hundreds of workers were left out in the cold. Especially hard hit were “undocumented workers,” workers in Canada illegally.

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833. SARS Commission Public Hearings, November 18, 2003.

While they were out of a job, they had no access to unemployment insurance or other governmental benefits. They also could not or would not complain to the authority when their rights were being violated.

The clinic filed a formal complaint against the Immigration and Refugee Board, where staff started wearing masks at hearings for Chinese or other Asian claimants. These claimants had been in Canada for at least a year, since that is how long it takes for a claim to heard, and were not recent arrivals. The practice was dropped after the protest.

Such experiences left many Chinese and Southeast Asians stigmatized and humiliated. This simply should not happen. Communication and education are the keys to avoiding such stigmatization. Intelligent people who have been communicated the real facts know better than to participate in such shameful shunning. Time and again the Commission has seen that preparation in communicating clearly and effectively could have avoided many of the problems that arose during SARS.<sup>834</sup>

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834. SARS Commission Public Hearings, November 18, 2003.