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Telling the story of SARS: Compassionate oncology care in the face of a futuristic health crisis

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Introduction

(presented by Pamela Savage)

On behalf of my colleagues, Janice Stewart, Colleen Johnson and Carolyn Saunders, we would like to thank CANO for the opportunity to share our experience on how oncology nurses can make a difference in a time of crisis. We would also like to thank AMGEN for the sponsorship of the Helene Hudson lectureship.

Princess Margaret Hospital (PMH) is located in downtown Toronto, Ontario. Together with the Ontario Cancer Institute, PMH is a member of the University Health Network, which also includes the Toronto General Hospital and the Toronto Western Hospital. It is the only facility in Canada devoted exclusively to cancer research, treatment and education.

The patient volumes at PMH are very high. The hospital sees about 10,000 new patients a year and has 130 inpatient beds, which includes both allogeneic and autologous bone marrow transplants. On a daily basis, 500 radiation treatments, 130 outpatient chemotherapy patients and 30 outpatient blood product transfusions are given. In total, 190,000 patients are treated annually as outpatients for diagnosis, treatment and follow-up.

The health crisis

On March 26, 2003, the province of Ontario declared a state of emergency due to the outbreak of Severe Acute Respiratory Syndrome (SARS). SARS is a viral respiratory illness caused by the coronavirus. It was first reported in Asia in February 2003. The illness then spread to more than two dozen countries in North America, Europe and Asia before it was contained. The signs and symptoms of SARS include: temperature greater than 38.0 C, headache, general malaise, mild respiratory symptoms at the outset, diarrhea, dry cough, and most patients develop pneumonia. As you all know, many of our oncology patients present with similar or identical symptoms.

By March 30, 2003, all Ontario hospitals were directed to activate their Code Orange emergency plans. Code Orange indicates an external disaster. It describes the plan for establishing a chain of command and control, mobilizing resources and allowing many affected facilities to minimize or

eliminate non-essential services. Unfortunately, activating Code Orange also paralyzed most of the medical care system in Ontario.

The first step of Code Orange directives was to restrict entry to the hospital to only those employees who were considered "essential" which meant those who would be able to provide what were deemed essential services. Given the complexity of the organization, which includes the research department and the staff of Cancer Care Ontario, it was difficult to decide who was "not essential". Despite our best efforts to identify non-essential staff, we still screened more than 2,000 staff a day, so we needed staff to help with the screening at both the employee entrance and the patient entrance. Since the hospital was restricted to one employee entrance, researchers and Cancer Care Ontario staff were requested to enter the hospital after 10 a.m. to accommodate screening the patient care staff first.

By the end of May, we would screen approximately 4,000 staff, patients and visitors because, by then, outpatients could bring one person to help accompany them and inpatients could have one visitor a day.

We quickly discovered that there were many people who entered the hospital who were not staff or patients including delivery people. These were customers to the coffee shops; people using the bank machine; people buying hospital lottery tickets, etc. This all had to stop and alternatives needed to be created to meet some of these needs until the Code Orange was lifted.

To get SARS you needed to be in close contact with someone with SARS. This, of course, is what put health care providers at such high risk, especially family physicians and staff in the emergency departments and walk-in clinics. Therefore, entry and exit from the hospital was through one entrance only and was separate from the patients' entrance. Staff needed to be screened daily for SARS symptoms and, depending on the screening criteria, may have been denied access to the hospital. If an employee exhibited one symptom, such as a temperature greater than 38.0, they were escorted to occupational health and assessed for possible quarantine at home or a more in-depth assessment was performed and possible admission to a "SARS unit".

As further protection, any person entering the hospital was required to wear a mask. Staff was required to wear gowns, gloves and goggles at all times while in the in-patient care areas. Screeners were required to have full protection on at all times. Staff members were not allowed to meet with each other for meetings, lunches or

Helene Hudson - 1945-1993

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parties in the hospital setting or outside the hospital and were restricted to working at one hospital. This restriction had enormous implications to the livelihood of many individuals.

The impact on many of the patients was devastating. Appointments not deemed essential were cancelled, so any new appointments, follow-up appointments, coming to the hospital for bloodwork, investigational diagnostic tests were stopped. Referrals, unless deemed emergent or life threatening, were delayed indefinitely. The implications to all hospital patients in Ontario were enormous, but to patients of a cancer hospital they were, in many cases, potentially life threatening. Therefore, despite SARS, chemotherapy treatments and radiation treatments needed to continue. The impact on the patients who were actually allowed to enter the hospital was great. Patients' family members were not allowed to enter the hospital, so the process of patients entering the hospital alone was often overwhelming and frightening to many. All patients needed to be screened before access into hospital was allowed. At the beginning of the Code Orange, there were no food services, no access to vending machines, etc. This was less than satisfactory, as many of the patients were required to spend many hours in a day to receive their treatments. Not having access to food and beverages was difficult for them.

Patients in the hospital felt very isolated. The restrictions imposed by this crisis required that their hospital room doors be closed at all times, they needed to wear a mask when anyone was in the room and they were not allowed visitors. At one point, they were not even allowed to receive packages from home. Once patients were discharged, they were placed in quarantine and, if they became sick, they were often reluctant to come back to the hospital.

So how did SARS arrive in Toronto? (See Photo One)

As many of you will recall, SARS came to Canada via a traveller. The "index" patient, a professor visiting Hong Kong from Guangdong Province in China, stayed at the Metropolitan Hotel and infected 11 persons from six different countries. One of the infected persons was a woman from Toronto visiting Hong Kong for a family wedding who had the misfortune of staying at the Metropolitan Hotel. This woman became the "index" patient for Toronto. She returned to her home, was very ill, and died within days of her return from Hong Kong. On March 7, 2003, the son of the "index" patient unfortunately developed similar symptoms and sought medical attention at Scarborough Grace Hospital, which is a hospital in the suburbs of Toronto. In the process of trying to find out what was wrong with the son, the virus spread to the son's family and their family physician as well as to two male patients at Scarborough Grace Hospital. Unfortunately, the son succumbed to the disease and three of the family members were hospitalized with the unknown respiratory illness by March 16. The two men who were in contact with the son transmitted the virus to many individuals before it was detected, which resulted in the wide spread of the virus in Toronto.

Just as the people of Toronto and the health care system were recovering from the first SARS outbreak, we experienced "SARS 2" on April 28, 2003, about a month after the first known "index" case (See Photo Two). The second "index" patient was admitted to North York General Hospital, a nonteaching hospital in the north end of Toronto. It is not clear how or where this person initially was exposed to SARS but by May 20 (that is 23 days later), SARS had infected patients and staff in six Toronto Hospitals, including the Toronto General Hospital (TGH), one of our three hospitals in the University Health Network. It was necessary to close the TGH emergency department for approximately two weeks due to a number of staff having to be quarantined due to a known exposure to a patient with SARS. By July 2003, approximately four months after the outbreak, 23,000 people had been

quarantined in Toronto, more than 2,000 persons were investigated for possible SARS, 358 patients had a confirmed diagnosis of SARS and 42 people died as a result of the coronavirus infection.

Compassion in crisis: Challenges and solutions

(presented by Janice Stewart)

Princess Margaret Hospital (PMH) did not officially close its doors on treatment and only closed to new patients for the first two weeks of SARS. What were some of the challenges and solutions that we experienced while delivering compassionate care in the face of this crisis? Imagine coming to your hospital greeted by huge STOP signs covering the windows of the entrance. There was fear and uncertainty. It was very noisy, confusing and frightening to enter the hospital and, for patients, this was in addition to the anxiety of having just been told they have cancer.

Photo One.

Photo Two.

Coming to PMH during the outbreak was a real challenge for all patients. Patients, on arrival, were told to put on a mask, wash their hands and leave their family and loved ones outside in the cold. Remember, this was March to May and it was a cold spring. Staff wearing a mask, gown, goggles and gloves greeted them. Sometimes, even if patients knew the staff person, they could not figure out who was speaking to them. Upon entering the building, they were faced with a very hectic environment. An average of 150 patients per hour were screened in the early days and towards the end of the crisis upwards of 300 people per hour.

During the summer of 2003, a group for students hired as SARS screeners helped conduct a study titled "Addressing Patient Concerns about Visitor Restrictions During SARS: What can Hospitals do?" under the direction of Dr. Joyce Nyhof-Young from the Patient Education Program at PMH. This study interviewed patients and family members, and some of their quotes are:

"I was really green and don't know much. I...didn't know how to do anything, and the five weeks I was there, the people couldn't have been better. And I know that with the SARS going on, there was a lot of issues going on, a lot of things happening. And they made me feel really comfortable. And I wasn't worried about going back every day. So it was great." (Dr. Joyce Nyhof-Young, 2003)

Humanizing an assembly line

On arrival at PMH, patients had to say good-bye to their family member, put on a mask and wash their hands before entering the building. Once in the building, the patients had to complete a form, have their temperatures taken and then be assessed by a nurse or a physician. (The presence of medical and nursing staff as screeners was unique to PMH compared to many other hospitals).

The screening tool included asking the patient whether they were experiencing muscle aches, severe tiredness, or feeling unwell, severe headache, cough, shortness of breath, feverish. Imagine how many cancer patients would answer "yes" to these questions. A large percentage of outpatients would be deemed as a "fail", meaning they would not be able to enter the hospital. For example, a patient with lung cancer and a cough, or a patient with a fever would technically be refused entry and be sent to a SARS clinic – once this occurred, they would be assessed and placed in quarantine and, despite having been cleared as non-SARS, would then be unable to access the cancer system for 10 to 14 days. This really placed hospital staff with a difficult task of determining the etiology of the patient's symptoms. It required the use of refined assessment skills.

Coordination of the screening process by a designated nurse coordinator included staff scheduling, interpreters, and correctly identifying the complement of physicians, registered nurses, social workers and volunteers. The coordinator triaged patients and had to deal with unique situations such as helping a confused patient with a brain tumour navigate his way through the hospital and decreasing the anxiety of a father who presented himself as a doctor to accompany his newly diagnosed son for his first appointment. She also had to deny a male patient access to a gynecologist that the patient insisted he was to see for treatment.

We also had to be very sensitive to the patient's interpretation of what the terminology "pass/fail" meant. Many were fearful that a "fail" designation meant they would not be cared for and, whenever possible, staff used alternative terminology. For example, if a patient "failed", it meant they required additional assessment, not refusal of entry. Security and public relations protected patients, family members and staff from the media who were constantly at the hospital entrance.

The department of nursing lobbied for the discontinuation of masks for those patients without respiratory symptoms. Lobbying was important as PMH is one of three hospitals in the corporation and it was difficult for one hospital to make a change that the other two hospitals did not.

The reasons for the lobby were that all staff members were suitably protected using N95 masks and many patients were not wearing their masks appropriately. Also, many patients complained about the masks increasing their feelings of nausea and shortness of breath.

Alleviating fear in fearful times

Patients would hear from the media that they should not come to the hospital if they had a cough or a fever and yet where should they go? Patients were reticent to go to the emergency departments or family doctors, hence they came to or contacted PMH once they were very ill with symptoms. When they did arrive at the hospital with a fever or cough, their symptoms raised concerns to other patients and staff. Patients and staff voiced their concerns loudly and frequently...because they were fearful that their health would be jeopardized.

"It was very hard at the beginning...Father doesn't understand English at all. So he was very scared that he won't know how to get to the proper room, that he won't understand what they are saying to him." (Dr. Joyce Nyhof-Young, 2003).

From this quote you can understand the level of fear and anxiety for patients and their family members whose first language was not English.

"SARS Fact Sheets" were available in many different languages to help alleviate the fear of the unknown experienced by patients and their families. Many of the internal staff served as interpreters and, in addition, we also used family members who were often called at home or work to interpret for their loved one. We found that communicating to patients in their own language helped alleviate their fears of this difficult and new process. Although many patients welcomed the removal of the masks, it did leave a small number of patients anxious that without a mask they were at risk of becoming infected. Masks were made available to patients on request, and continued to be available to them. Handwashing was very strict and is maintained to this day. This process helped to reduce fears of developing SARS.

Communication when you can't

"It better with no mask,...cause I look at the mouth when she talk, because it easier for me to understand." (Dr. Joyce Nyhof-Young, 2003).

We communicated with the patients and families in a variety of ways. When family members were not able to enter the hospital, we would use a walkie-talkie or cell phone to facilitate communication between the health care team and the patients and the family. Walkie-talkies lacked confidentiality, but worked in a pinch. Cell phones often presented issues with service due to the surrounding buildings.

The language line was a service initiated with SARS at PMH that allowed us immediate access to a professional interpreter via the phone. It was excellent and fast. Before the availability of the language line, other innovative strategies such as contacting associations or agencies that could interpret were utilized. For example, in one situation, a woman from Ethiopia entered the hospital, but it was not clear what language she spoke. She required a breast biopsy and we needed not only to screen her for SARS, but also needed to figure out what she was coming to hospital for and obtain an informed consent. She had come by herself from a woman's shelter and, after much searching, staff was able to locate a young male interpreter to assist in the translation.

"They (the staff) told me at that time, you bring him, but you cannot come in. But don't worry about it, because we have a lot of staff inside to take care of him. And there is coffee outside and soft drinks too, and there is a trailer where you can stay...I stayed outside...they (the staff) did everything possible to accommodate us..." (Dr. Joyce Nyhof-Young, 2003).

Navigating using old maps

The Code Orange restrictions forced us to create new and innovative ways to assist patients in navigating the health care system. Triage at the door allowed us to assure patients and staff that every precaution was being taken to protect people from any potential disaster. It also allowed hospital staff to identify ill patients and streamline their access to the medical services. The lobby was reorganized a number of times in an effort to maintain confidentiality and improve flow. A unique feature during this crisis was that we needed to keep our oncology doors open to patients from other hospitals, which normally was strictly prohibited

under Code Orange. Ambulance transfers became a big concern as ambulances travelled between many health care institutions and, therefore, could easily and unknowingly infect several hospitals if appropriate precautions and restrictions were not strictly followed.

Sensitive to visiting in restrictive times

The Code Orange imposed visiting restrictions that were not designed for the oncology population, nor was it compassionate to this population. The visiting restrictions were met with much resistance and sadness.

No visitor policy – a family member's response:

"I was very mad! I mean, I know that this was all for safety precautions, I understand all that, but you know, when somebody in your family is alone there, then you feel angry at a certain point...you would wait outside and you don't know what he is doing in there..." (Dr. Joyce Nyhof-Young, 2003).

No visitor policy – information provision:

"I couldn't understand anything. I didn't get any information because I was just too stressed being there by myself...[My husband is] so involved in my care...He is there for every appointment. He knows every answer and he has questions. ...I wanted him there. I wanted him there!" (Dr. Joyce Nyhof-Young, (2003).

The Code Orange directive mandated a no visitor policy for more than six weeks. Once the restriction was changed, the inpatients were allowed one visitor a day from 1700 hours-1900 hours. In late May, two visitors were allowed per day for patients in the hospital.

How we made a difference

Bending the rules while maintaining safety was a repeated theme as we tried to make the situation easier on patients and family members. Early in this crisis, patients were supposed to enter the building alone, but PMH always allowed the pediatric patients to be accompanied by one parent. For compassionate reasons, patients on the palliative care unit could have two visitors at any time of the day or night. To assist in communication, physicians and nurses would go outside to speak with family members. A trailer was erected outside to protect patients and family members from the elements. This trailer ended up being used for wig consultations, child minding, and family meetings. Technology in the form of telehealth and web cam visiting was also utilized. The "Caring Websites" were supported by the PMH Foundation, which were and continue to be available for patients to develop their own websites as a means of communication with family and friends.

Happy staff = Happy patients

Keeping enough supplies for protective gear on hand for staff was important to keep them happy. The amount of supplies needed was staggering. For example, on an average day 10,000 to 15,000 masks, 15,000 to 20,000 gloves and 3,000 gowns were used. More than 6,000 goggles were ordered and used as well as countless boxes of no-rinse hand cleansing gel and virox wipes.

While the protective gear was important for many, the use of facemasks resulted in a red chin and nose and for some a facial rash. Due to the increased handwashing, many staff experienced dry, raw

hands and contact dermatitis. To counteract the inconvenience and irritation of the protective gear, frequent breaks were encouraged and supported. It was important, if staff were eating in the same lunchroom or taking a break at the same time without protective gear, that they were required to be one metre away from each other. There was no cafeteria or any retail stores available in the hospital, but the nutrition department provided water and juices for staff. Even the purchasing department needed to be creative in their purchases. Supplies such as antifog spray for goggles and magnification stickers to place inside goggles for reading were requested by many managers. Mask fit testing was initiated to ensure that all staff were wearing the most protective mask possible for their facial structure. To decrease the burden on health care professionals, managers were encouraged to increase their daily staffing. Command centre was available to staff 24 hours a day/seven days a week to answer or address any concerns. It is well-known and proven that if all staff is well-informed, patients receive better care. Our Vice-President of Professional Affairs and Chief Nurse Executive used an innovative strategy to communicate with all staff by the intranet using cameras instead of e-mail.

It's over!

Finally, we needed to celebrate and recognize our achievements and hard work. One of the fun things we did once the Code Orange was lifted was a staff barbecue. Thank you notes and e-mails were sent out. Gift certificates were offered to many staff as well as tickets to professional baseball games and discounts to the local hotels, theatres and restaurants. The hospital also recognized staff and volunteers with gold lapel stars to acknowledge contributions made during the SARS crisis. The city organized the SARS concert that commemorated the 42 people who died and raised money and awareness of how the city, communities and businesses had been affected by the SARS outbreak.

The unique skills of oncology nursing proved to be valuable during SARS. Oncology nurses always balance the needs of the patients and patient safety. As oncology nurses, we are always on the lookout for life-threatening infections. Oncology nurses are experts at teaching our patients how to manage uncertainty. ♣

Acknowledgements

The authors wish to thank many staff and volunteers at PMH for their courage and compassion in helping their fellow colleagues, patients and families deal with the SARS crisis. We would also like to thank the many patients and their families who maintained their trust in us to deliver to them the very best care.

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References

- McGeer, Allison – personal communication
Nyhof-Young, J., Jusko Friedman, A., Wiljer, D., & Catton, P. (2005). Addressing patient concerns about visitor restrictions during SARS: What can hospitals do? *Longwoods Review*, 2(4), 9.
Svoboda, T., Henry, B., Shulman, L., Kennedy, E., Rea, E., Ng, W., et al. (2004). Public Health Measures to control the spread of severe acute respiratory syndrome during the outbreak in Toronto. *New England Journal of Medicine*, 350(23), 2352-2361.

- <http://www.cdc.gov/ncidod/sars/factsheet.htm>
<http://www.bienejer.mil.ar/sanidid/img/corona.jpg>
<http://www.optotherm.com/Corona-Virus.jpg>
<http://www.uhn.ca/index.asp>