SOCIETY

The pandemic has disrupted death and mourning in ways we don’t yet understand

The act of being present for a dying loved one can be an initial processing of grief, but often family members of coronavirus patients aren’t allowed visits until the very end. COVID-19 may be setting the stage for a 'tsunami of grief.'

By Christina Frangou
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Ramey (top left) with her children (clockwise from top right), Tonia, Elijah and Suriya (Photograph by Chloë Ellingson)

For five weeks and three days this spring, Dave Varghese’s children waited for their dad to come home.

Tonia, 26, Suriya, 8, and Elijah, 5, couldn’t visit him in the hospital because of restrictions to prevent the spread of COVID-19, even though he did not have the virus. They saw their 43-year-old father once on an evening when the staff worried he might die. He didn’t, but he didn’t get better either. Every day, Varghese’s wife, Heather

Ramey, arrived at the hospital for a one-hour visit. Staff checked her temperature at the entrance and screened her for symptoms; then she'd walk to Varghese's room, where she bathed him. They dealt with his financial affairs. Sometimes she urged him to come home to their house in Burlington, Ont., and to stop the radiation treatments that didn't seem to be helping. In trade, she said, he'd get more time with their kids.

Varghese, who had testicular cancer that metastasized to his brain, came home around dinnertime on May 5, when there were no more treatments to be tried. He spent a wretched night writhing in agony on a hospital bed in the family living room. His pain medications were not delivered to the house on time.

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When the sun rose the next day, Ramey woke the kids and sent them down the street to her brother-in-law's house. She didn't want them to see their dad in pain. He was panting in distress. Later that morning, after his medications arrived, Varghese settled mercifully into sleep.

An exhausted Ramey sat down at the kitchen table. The palliative care nurse went to check on Varghese. After a few minutes, the nurse walked back into the kitchen. "He's gone," he told Ramey. "I'm so sorry."

Now the kids are waiting for a funeral. They want a party for their dad with lots of people in the backyard, just like the pool parties he liked to throw. Elijah saw a photo from his parents' wedding and started crying that he misses his daddy. Suriya wants to go back to school where she could see her best friend and everybody in her class would hug her. Ramey wants a ceremony for the kids so they can lay their dad's urn in the ground and people can say a few words about Varghese, who was social and loud "to the point of being pushy," she says. "It's sad that my kids can't witness other people being sad about their father dying. I think that would be comforting to them."

Their grief is locked in a kind of quarantine with no one to share it with. "I can't hug my parents. My children can't hug their grandparents. My in-laws have lost their son and they can't hug us," said Ramey.

Varghese with Elijah and Suriya in a Star Wars-themed photo taken before he went into hospital (Crystal Bell/OhSoBeauty Photography)

The Rameys are among tens of thousands of families in Canada who are grieving a loved one in the time of COVID-19. The virus, which has killed 8,639 Canadians as of July 1, has disrupted dying and grieving for all these families, regardless of the cause of death.

“This is not a good time to die,” says Dr. Harvey Chochinov, a psychiatrist and director of the Manitoba Palliative Care Research Unit in Winnipeg. Chochinov estimates that, since the pandemic was declared in March, 60,000 to 70,000 Canadians have died from causes other than COVID-19. Each of those deaths has, in some way, been tainted by the pandemic, which has limited visits in hospitals and long-term care homes, and led to restrictions on public memorial services, as well as high levels of stress across the population. Even the most elemental offering of comfort to another human being—touch—is off limits to all but the innermost circle. Grief, in and of itself, is an isolating experience; grief in the context of a pandemic that necessitates physical distancing and is raising death rates may be unprecedented in scale, complexity and loneliness.

For every death, about five people are profoundly affected, says Chochinov. By that estimate, about a million and a half Canadians in the first year of this pandemic will be forced to deal with a kind of grief “the likes of which we’ve never seen, and can’t pretend or claim to understand.” He predicts that we “are facing a tsunami of grief ahead.”

Complicated grief, which occurs in about seven per cent of bereaved people, is more than just a prolonged period of sadness. Associated with depression, suicidality, social isolation and post-traumatic stress disorder, complicated grief derails the grieving process. Some people experience ongoing panic or anxiety attacks, or excessive worry. They ruminate on what has been lost. Some constrict the boundaries of their lives in order to avoid places they went with the deceased. Positive emotions, when they come, can be coloured with guilt.

Studies done before the pandemic found that families who do not have a chance to say goodbye to their person before death are at higher risk for complicated grief. The same is true for the loved ones of people who die in hospital or in intensive care units compared to those whose loved ones die at home. In a report published in the *Journal of Pain and Symptom Management* this past spring, experts in palliative care wrote that the circumstances around COVID-19 may "set the stage" for complicated grief to occur after death because of increased levels of anxiety and depression related to the pandemic, ethical decisions about triaging resources, quick transitions between "ill" and "dying" in previously healthy people, and limitations in visitors who can be physically present at the bedside.

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Dr. Margaret Pabst Battin, an ethicist at the University of Utah who is an expert in end-of-life care, foresaw the difficulty caregivers are facing during COVID-19. In a 2008 book called *The Patient as Victim and Vector: Ethics and Infectious Disease*, she wrote about the ethical challenges that could arise during a pandemic. The title describes precisely the situation the world is now in: the person who is dying might transmit an illness that could sicken or kill their caregivers; likewise, caregivers might do the same. In an interview this spring as part of a series of talks on ethics co-sponsored by the University of Calgary's Institute for the Humanities and Calgary restaurant Sidewalk Citizen, Battin said that the decision to restrict visitors to hospitals and nursing homes prioritizes safety above other values, including the value of human connection. It's not clear yet what the long-term consequences of these restrictions might be on bereavement.

"To say that we can't let anybody in [to hospitals] seems to me to be overdoing it—[prioritizing] long-shot risks of threats to safety over clearly important, present and utterly valuable human communication right at the moment," she said.

The act of being present for a loved one who is sick and dying can be both an act of care and an initial processing of grief. Battin knows this first-hand: when her husband became paralyzed after a severe cycling accident in late 2008, she cared for him at home for almost five years, managing his ventilator until he made the decision that he wanted to die in 2013. And, so do I: I lived with my husband for weeks in hospital before he died from cancer in the summer of 2013, just before Battin's husband's death.

To be present at a death, and the days and the hours leading up to it, is no small role; the responsibilities are many. There are things that doctors and nurses cannot do. Sit vigil. Watch for the small changes. Hold hands and rub feet. Say the things that need to be said. Speak for your person when they can no longer speak for themselves. Advocate for them. Dab dying lips with wet sponges. Say things like "I love you" and "thank you" and "I promise you that we'll be okay." While these gestures are not curative, they can be a salve for the dying and the soon-to-be bereaved. These are life-changing things to be done when lifesaving is no longer an option.

But these last acts of care are off limits to many families during COVID. "The part of not being able to be there to say goodbye—I think it's going to be devastating," says Dr. Hsien Seow, Canada Research Chair in Palliative Care and Health System Innovation at McMaster University. When someone is dying, there's often a moment where families realize that time is suddenly very short, he says. People begin to share things that they always thought they'd have more time to say. "If they are robbed of that opportunity, survivors and families will carry that with them forever," he says.

Since the pandemic began, some families have gone to extreme lengths to be there for their loved ones. Cherie Kok travelled to Cuba for a vacation in early March and by the time she returned home to Thunder Bay, Ont., COVID-19 had changed her community, though there were no cases locally. She couldn't get into her parents' nursing home because she'd been out of the country. Ordinarily, she visited her parents daily.

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When her 81-year-old mother stopped eating, Kok carried a ladder to the chain-link fence surrounding the nursing home's property line. She tossed a lawn chair and a water bottle over and then clambered over herself, ripping her pants in the process. She pulled her chair up to her mom's ground-floor window and talked to her through the screen. Her mom turned her head to the window at Kok's voice. "I don't know where I'd be today if I didn't know she heard me," says Kok. For the next two days, Kok returned to her mom's window. Inside the room, Kok's closest friend from childhood sat with her mom, holding her hand and stroking her hair at Kok's request.

Around 1 a.m. on March 21, the nursing home called to tell Kok that her mom had died. Worried that her mom had suffered, Kok asked her brother to review the footage from the webcam in her mother's room from the hours before her death. Then she watched the footage herself: about an hour before staff called, two personal support workers stood in the room with her mother, holding their hands to her forehead in comfort. After they left, Kok's mother took two more breaths and died.

Kok has not been able to see her father for 3½ months; after her mom died, the province tightened the rules. She doesn't know if he understands that his wife of 53 years died across the hallway from him. She can't pull a chair up to his window. But a recent rule change in Ontario means Kok will soon be able to see her father outside once a week, provided she tests negative for COVID-19.

Families dealing with deaths from the coronavirus are grappling with additional layers of complexity. The rules vary from place to place, but family members often aren't allowed visits until the very end of life. By then, their person might look dramatically different from when they last saw them, says Dr. Ken Parhar, an ICU physician in Calgary who has cared for patients with COVID. In some places, families have to select one person as their representative—a child? A spouse? A sibling? When that person enters the room, they're not always prepared for seeing the life-support machines. "Then they realize what their loved one has gone through, and it's a lot to take in," he says. "You're struggling with the fact that your loved one is going to pass away. But at the same time, you're also struggling with thoughts like, 'I can't believe I haven't seen you for four weeks and you had to be in the hospital bed all by yourself during the day and at night.' "

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The infectious nature of the virus increases the likelihood that multiple family members will get it and may die from it. Dorothy Vaughan, 82, lost her twin sister, Doreen "Dean" Gauvreau, to COVID-19 in April, and then her husband a few weeks later. Doreen's husband of 61 years, Sylvio Gauvreau, also tested positive for COVID-19, but recovered. All three lived in the McKenzie Towne Continuing Care Centre in Calgary; Vaughan resides across the street at the affiliated McKenzie Towne Retirement Residence.

Vaughan learned about the deaths of her sister and husband when her daughter, Nina, told her over the phone. "My poor mother just cried for hours on FaceTime, and I watched her cry, completely unable to comfort her. Just sat and watched," says Nina.

Nina Vaughan's aunt died alone, after a short visit with her daughter. Later, when Nina's father was dying, she was allowed to see him for the first time in weeks. She refused to leave. “When I went in, I said, ‘You’re not getting me out of here until he is dead,’ ” she says. That was the first time she understood what her father and aunt, who both had dementia, had gone through, with their caregivers dressed head-to-toe in personal protective equipment that made them unrecognizable.

Like the Ramey family, the Vaughans are waiting for a ceremony to bury the remains of their family members. Nina wants to take her mother to New Brunswick to spread her father’s ashes. But she’s uncertain about taking her on a plane and then quarantining for two weeks after they land. If the trip works out, Nina’s mother might not be able to return to her retirement residence after the trip. Nina, who had debated bringing her mother to join her at home in her apartment after her father died, was told that if her mother leaves the residence, she can’t go back until the pandemic ends or the risk of infection is lower. “The inability to have a funeral has added another layer on top of trying to find any sort of closure,” she says.

Health-care workers, too, are struggling from the effects of not having families in the room. The paradigm of medical care, especially at the end of life, includes both patients and their families. For more than a decade, family members have been welcome in many intensive care units, often around the clock—a recognition of the role that they play in assisting with patient care, acting as surrogate decision-makers and emotional supports for patients, says Dr. Kirsten Fiest, the director of research and innovation in critical care medicine at the University of Calgary. COVID-19 changed those policies overnight. “What I’ve heard from my colleagues is this is absolutely devastating, causing moral distress in the care providers and family members. It’s totally against what I perceive to be the biggest advance of medicine in recent years, which is patient- and family-centred care.”

Fabreau has held up an iPad so dying patients could talk with family: 'It's heartbreaking' (Photograph by Candice Ward)

Twice since the pandemic began, Dr. Gabriel Fabreau, an assistant professor of internal medicine at the University of Calgary who works in the COVID-19 unit of Calgary's Peter Lougheed Centre, held up an iPad for a dying patient so their family could speak to them through FaceTime. It was hard to hear because oxygen hissed in the background. Even though the iPad was turned up to the maximum volume, it was not loud enough. A family member cried on screen and asked Fabreau to readjust how he was holding the device. Fabreau cried when it was over. "It's the opposite of good palliative care," he says."It's heartbreaking for everyone. Palliating somebody with their family through FaceTime is moral injury. It is another form of vicarious trauma that we're going to carry as scars as a result of this thing." ICU physician Parhar says the same: "Not having families there, it's been the toughest part for me to deal with out of the entire COVID-19 pandemic."

None of the COVID-19-related mental health initiatives so far include support for grief. In May, the Canadian Grief Alliance—a group of Canadian leaders in grief and bereavement—called on the federal and provincial governments to bolster the country's grief services to meet the growing demand. The group has asked the federal government to invest $100 million in grief support over the next three years and $10 million in research. "We think the current mental health system is simply going to be overwhelmed and unable to handle it within the current resources that exist," says Chochinov, who is a member of the alliance.

A few days after her husband died, Ramey looked out her front window and saw her lawn covered with flowers. Two of his friends had ordered more than 50 pots of flowers to be delivered. People have gone to extraordinary lengths for her and her children. Their teachers organized Father's Day celebrations around her kids. A group of local dads set up a drive-by visit, with cars honking and waving at the kids. But it's not enough for a grieving family, she says. "I want something for my children other than this."