



We've Been Here Before: Learning from the Lessons of the Past

By Liz Crocker

COVID 19 is testing the capacity of our health care systems and the courage and emotions of many point-of-care health professionals. Hospitalized patients and residents in long-term care facilities are often suffering and even dying alone because of public health policies which have restricted the presence of family members or designated support person. Tragically, while these limitations may have been well-intentioned, designed to limit the spread of the COVID-19 virus and protect staff, they have usually been made without consideration of the harmful consequences which have been detailed in previous pandemics.

In 2020, we are living through a terrible push-pull between two approaches: (1) encouraging patient/family collaboration and presence; versus (2) protecting the public good. The 'protecting public health' choice to limit access to hospitals and long-term care facilities only to staff, thereby restricting family members from being with their loved ones, is based on a premise the benefits of such restrictions are greater than the good that can come from carefully managed connections among patients, families and health care providers. But is this the right choice?

In 2020, virtually overnight, most hospitals and other health care institutions have significantly scaled back commitments to "patient- and family-centered care"...that health care encounters are dignified, respectful, collaborative and based on timely, complete, and accurate information to enable patients and families to effectively participate in care and decision making. These commitments related to patients/families/staff collaboration have been compromised, overwhelmed, and paralyzed.

Sadly, we have been here before. In our haste to 'protect everyone', we have ignored some of the lessons from the past.

“Overnight, hospitals went into what felt like a lockdown mentality: Entry points were limited; all patients and staff were screened for symptoms and security personal 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...overnight health care professionals became bigger, taller, wider, and more removed from their patients because of protective clothing. Overnight people became afraid.”

This quote is written in the past tense because it was written about the 2003 SARS outbreak and taken from a chapter titled 'It Was As Hard As It Gets' in *Privileged Presence: Personal Stories*

of Connections in Health Care first published in 2006. It could have been written again during the H1N1 pandemic of 2009.

Subsequent to both outbreaks, patients, families and health care staff pleaded for better preparation for future pandemics, for the creation of policies and practices that would be responsive to public health concerns AND also recognize that family members or other designated “partners in care” are stewards of patient safety, psychological support, and enhanced recovery. In 2003 and again in 2009, story after story described that the absence of attentive family members being present with their loved ones in hospitals led to already overworked staff having to shoulder additional burdens of trying to provide emotional care for patients who were ill, frightened and vulnerable. As a result of both pandemics, many staff identified symptoms of post-traumatic stress disorder and needed help to recover.

Both the SARS and H1N1 experiences provided informed bases for planning for the future to avoid the profound emotional side effects of family separation and patient isolation. Think of a woman in intensive care (for medical reasons unrelated to the pandemic) who could not talk and was going blind – overnight her husband was told he can no longer be with her and overnight staff were robbed of someone who could help interpret what this woman was trying to communicate. Think of an 18-year-old young man who had been in a car accident, suffered a head injury and who was just starting to communicate again; his mother begged to be able to stay with him to support his challenging recovery but she was told that the virus was more important to consider than her unwavering and helpful love.

Can past experience be a teacher? Can we learn from those who have begged us to consider these strategic questions when we see the storm clouds of a public health crisis looming on the horizon?

- Should restrictions to family presence at the bedside be applied in a “one size fits all” way or can we individualize approaches considering relative risks and consequences? Can units or wards be segregated to minimize the need for rigid infection control practices for all patients?
- How restrictive and for how long do limits on contact between patients, families and staff need to be in place? Do we have a system to adapt policies as situations rapidly evolve and change? How do we assess circumstances to weigh the risks versus benefits of restrictions to family presence?
- What support networks need to be in place for separated families and overwhelmed staff to mitigate the long-term effects of the emotional trauma associated with pandemics and limiting connections between loved ones?
- If restrictions have to be extreme, have we found ways to embrace technology to maintain contact, needed information, and support? When we say “no visiting”, are we prepared to explain how communication will be ensured and everyone supported as effectively as possible?
- Can we support a family member who chooses to ‘shelter in place’ with their hospitalized loved one for the duration of the hospitalization ensuring the family member knows he or she will have to quarantine following a return to home?

- If policies designed to protect public health are seen to be causing harm, what changes need to be made to avoid harm and what supports can be put in place to ensure healing?
- Do staff have ways to discuss the challenges they are facing and receive appropriate support?
- Is there a mechanism to learn from other institutions that are using innovative ways to practice patient- and family-centered care during public health crises?
- When patient- and family-centered policies and practices have been put on hold, can we partner with patient and family advisors to ensure that their perspectives can inform changes to policies and practices?
- When restrictions to family presence and involvement have been enacted but are determined to be no longer necessary, what is the strategy to welcome and ensure a full return to compassionate and collaborative care policies and practices?

We have been living with COVID-19 for months and so one might ask ‘Why ask these questions now? Isn’t it already too late and hasn’t the damage caused by separating patients and families already been done? Haven’t patients already suffered and/or died alone? Aren’t health care workers already showing signs of phenomenal stress and emotional trauma?’

The answer to “why now?” is simply “why not now?” Just because policies have been put in place that have eliminated patient- and family-centered practices doesn’t mean that we can’t look at these limiting policies and ask if this is the best way to go forward. COVID-19 is still with us, all signs point to a likely ‘second wave’, and future pandemics are a certainty. It is both prudent and wise to ask ourselves what we have learned from 2003, 2009 and again in the last couple of months so that we can be better prepared.

What has worked well in terms of public health objectives and what needs to be improved in terms of the emotional well-being of patients, families, and staff? Can we be careful and compassionate at the same time? Can we protect and engage at the same time? Do we understand that there might be a difference between simply protecting lives and ensuring that people can thrive? Have we asked patients, family members, and staff what they would like to change for a second wave?

Should anyone ever die alone? If a compassionate nurse is going to hold the hand of a dying person, couldn’t a family member be allowed to hold that hand? Should a laboring woman ever be forced to give birth alone and/or be separated from her newborn baby? Should any patient of any age have to experience being ill or injured and be denied the physical and emotional support of loved ones?

Do we fully understand the emotional side-effects of the public health restrictions we’ve been using? By placing concerns for physical health over mental health, are there repercussions we have not anticipated? If so, what can/should we change? If someone is on a clinical unit with absolutely no evidence of COVID-19, can “rules” be careful and protective without being fierce and based on denial of access? And are there health care institutions that have managed to combine safe public health guidelines while supporting the core elements of patient- and family-centered care?

When weighing the need to limit family presence, we must also consider that these policies might lead to unanticipated risks of harming the emotional and psychological health of patients, families, and healthcare staff. In a March 30, 2020 article in the Boston Globe, an ICU physician said, “Patients, even those not suffering from COVID-19, now suffer ‘in a medical version of solitary confinement’.”

A New York Times article on March 29, 2020 said “Clinicians and hospital staff said that keeping families away had been among the darkest experience of their professional lives. The restrictions run contrary to a hospital’s desire to keep patients and families together, not only for the salutary effect of something as simple as a hand held, or a chair pulled close to a bed, but because having a relative present can ease the workload of the medical team. It can also provide crucial information that a confused patient may not be able to offer.”

From a west coast hospital comes a story of a family who, one by one, were helped by staff to don and doff protective equipment to be present with a patient with COVID-19 who had been on a ventilator for four weeks and was thought to be doing poorly. This same patient recently left for home, headed for a full recovery; the acting administrator says it was the night of the family visit that lifted the patient’s spirits and turned this case around. Was this simply an act of kindness or a manifestation of a deep understanding about the importance of family connections? Love is a profound healing force and, even when patients do not make it, the expression of love helps heal those who survive.

Can we learn from these stories? Can we think fully what “First do no harm” means? Can we acknowledge the unanticipated harmful consequences of protecting physical health without full consideration of the emotional health consequences of being ill, scared, and alone? Do we understand the immediate and long-term impact of a family member being denied access to loved ones or a health care professional witnessing the trauma of enforced separation? Can we be brave? Can we be creative? Can we be committed to important ways of caring, being kind and showing compassion? Can we work together—health care leaders, clinicians, staff, patients, and family members—to develop guidelines and processes for future crises? Can we hear and act on the pleas of those who have gone before us and who have experienced earlier pandemics? We’ve been here before. Can we learn from the lessons of the past?

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Liz Crocker recalls being deeply troubled by the stories she heard while doing the research for the chapter about SARS in *Privileged Presence: Personal Stories of Connections in Health Care* and hoped that sharing those traumas and recommendations for change would lead to transformative learning. Again, in 2009, during the time of H1N1, she was part of a task force to write a guidance piece for IPFCC about how to respond during pandemics and honor the principles of patient- and family-centered care. Now, in 2020, she joins the chorus of patients, families, staff, clinicians, and administrative leaders who know, deep in their hearts, that we can do better.