REFLECTIONS ON PRACTICE

How COVID-19 has changed the dying experience for acute care patients and their families

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COVID-19 was officially declared a pandemic on March 11, 2020, altering healthcare practices in numerous ways. While adhering to mandatory physical distancing policies to prevent the spread of the virus, healthcare providers have been challenged to adapt to continuous changes in procedures while caring for patients. A notable unanticipated consequence of COVID-19 is the impact on palliative care practitioners treating COVID-19 and non-COVID-19 patients, especially in caring for patients at end of life. The pandemic has impacted the end-of-life care experience of hospitalized patients and practitioners in profound ways. These experiences demonstrate a greater level of loneliness, difficulties in decision-making and communication, and an intense emotional impact on patients, their families, and clinicians.

COVID-19 has, unfortunately, created a heightened level of loneliness for hospitalized patients at end of life. Prior to the global pandemic, a dying patient was able to have countless visitors with loved ones gathered at the bedside. Often times a support person might accompany a patient throughout the day or night. Unfortunately, this practice is no longer permissible during these unprecedented times. Hospitalized patients with COVID-19 are not allowed visitors, even when dying. Additionally, those dying patients who do not have coronavirus are limited to a maximum of only two visitors in their last 48 hours of life, with only one visitor allowed at a time. The allowance of visitors in the last 48 hours is especially challenging as, at that time, many patients are unresponsive, and meaningful communication with family is limited. Patients may also be demonstrating some of the more physically overt symptoms of the dying process, such as agonal breathing, upper airway secretions or terminal delirium, which can be distressing for families to witness. Therefore, the final moments families are spending with dying patients are hallmark by limited communication and, quite possibly, unsettling physical appearances.

The aim of the restricted visitor policies is stringent infection control by limiting the incidence of asymptomatic carriers into the hospital who could be carrying the virus. While these policies are wisely enforced for the greater good to prevent the spread of the coronavirus, the impact on patients and their families/friends can be devastating. Due to these new restrictions on visitors, patients and families have been faced with additional difficult end-of-life care decisions. In addition to prior difficult decisions patients and families often face at end of life, they must now make decisions regarding place of care with new implications. Families must decide between having their loved one at home and being in the presence of relatives, or have end-of-life care managed in an institution, knowing that family time would now be greatly diminished and restricted due to the COVID-19 visitor policies. Both options bring new stressors to families; highlighting the concern of more complicated grief after death.

Another important challenge faced by practitioners due to visitor restrictions, as a result of COVID-19, is the negative impact on communication between patient and family and between patient, family, and healthcare providers. Consequently, our institution introduced video conferencing methods to patients and their families and friends to promote and enhance communication. Both the social work and spiritual care departments have been integral in assisting patients with access to video conferencing, especially those who are not already virtually connecting. Virtual communication has replaced face-to-face in-hospital visits and phone calls and has provided comfort to some, but not to all patients. For patients suffering from a cognitive impairment, a video conference may create more confusion and anxiety. Regrettably, due to the restrictions to in-hospital visitors, the comfort of human physical contact and presence has been replaced by a more distant interaction of video conferencing.

With the lack of visitor presence in the hospital setting, nurses, physicians, and other allied healthcare staff strive to balance an increase in usual duties while simultaneously providing emotional support and physical presence to end-of-life patients. Through participation in video conferencing sessions between patients and families, healthcare providers cannot help but feel and absorb the added emotions in the room. A patient receiving devastating news cannot reach for the hand of a family member for confidence and assurance, is therefore left with the hand of their healthcare provider for...
support instead. When a video confer-
ence ends the heaviness of emotions
reverberate in the patient’s room and
the healthcare team spends the extra
time to fill the patient’s void of compan-
ionship. However, the hope for this new
initiative is that a loved one’s voice and
appearance can bring forth some level
of comfort and support during this try-
ing time.

Healthcare teams are learning new
ways of filling in the gaps through
new measures. However, there exists a
growing worry regarding the long-term
impact on providers as they absorb the
sense of isolation inside the hospital
on a continuous basis. While the use
of personal protective equipment (PPE)
is essential for healthcare workers, the
empathy that was once emitted by prac-
titioners through body language and
other non-verbal behaviours is greatly
diminished. While healthcare workers
are grateful to have the necessary PPE
during the COVID-19 global pandemic,
one cannot help but observe the further
remoteness imposed with its use, when
human contact with a distressed patient
is dampened by gloves, or the support-
ive smile of a colleague goes unnoticed
due to the mask hiding the human
expression.

The end-of-life trajectory for patients
can be unpredictable. The dying phase
can last longer for some individuals
and rapidly progress for others. The
restricted visitation policy brings new
added pressure on bedside nurses to
accurately prognosticate a patient’s
death. The timing for this is critical, so
that families are informed promptly and
do not miss an opportunity for a final
good-bye. Despite staff doing their best
to address this issue, some families may
be losing the opportunity to build final
memories and allow the natural griev-
ing process to begin. COVID-19 has iso-
lated hospitalized patients from their
families, and this isolation compounds
the suffering of both patients and fami-
lies. Prior to COVID-19, patients along
with their families had daily opportuni-
ties for memorable in-person visits and
for tending to various matters such as
reconciliations of relationships and legal
or financial concerns. Access to these
meaningful opportunities has become
more challenging. The demand is now
on healthcare providers to employ cre-
ative solutions and fill the voids felt by
patients and their loved ones as a result
of the pandemic. While healthcare pro-
fessionals are working hard providing
comfort and support, too often we leave
our institutions depleted emotionally
and physically. Our families witness our
dedication to patients and the cautious
reentry into the home, as we rush to
change clothes and shower, as the fear of
bringing the virus to our families is a real
concern. We return to our homes after
work, in which we strive to bring some
sense of humanity to an experience that
may have felt inhumane. Our familiar
institutions now feel eerily unfamiliar, as
we walk through quieter halls that seem
to echo with the absence of families and
visitors. We leave our strange new work
environments for an outside world that
is equally unfamiliar and strange with its
empty streets and desolate playgrounds.

Each day we ready ourselves for work
fueled by the continued desire to help
those in need, while knowing we will
be entrenched in a great deal of sadness
and despair. As difficult as it is working
in healthcare during the COVID-19 pan-
demic, the resilience and dedication of
our fellow frontline workers have been
nothing short of inspiring. Throughout
all of this, the strength and dedica-
tion of our colleagues, coupled by the
outpouring regard by our community
uplifts our morale, inspiring us to per-
severe and reenter those hospital doors
each day.