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Goals of Care in a Pandemic: Our Experience and Recommendations

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Abstract:
We propose that the palliative care team response will occur in two waves: first communication and second symptom management. Our experience with discussing goals of care with the family of a COVID positive patient highlighted some expected and unexpected challenges. We describe these challenges along with recommendations for approaching these conversations. We also propose a framework for proactively mobilizing the palliative care workforce to aggressively address goals of care in all patients, with the aim of reducing the need for rationing of resources.

A COVID Code discussion:

The palliative care team received a consult for "goals of care and depression" in Mr. W, a 74 year-old who had been hospitalized for heart failure exacerbation for about a week. Unable to respond that day, the patient was transferred overnight to the ICU. The patient was in airborne isolation and, we learned, was now being tested for COVID-19. Reaching out to the wife by phone, we offered support and asked about her understanding of his illness. We learned that she had strong healthcare literacy as a former ICU nurse, and we hoped this would provide an advantage in goals of care conversations. She was focused on getting approval to start experimental antiviral treatment for her husband, believing that this would aid in his recovery. Using the strategy of hoping for the best and preparing for the worst, we inquired as to her perspectives on code status, specifically CPR. Mrs. W. said she had "already discussed this" and wanted him to have CPR. She expressed concern that if she agreed to a DNR, he would not have the chance to benefit from the antiviral treatment. We gently explained that with a DNR, Mr. W. would continue to receive all medical care until the point his heart stopped, but his wife continued to express a desire that he receive CPR.

Challenges of Goals of Care Discussions:

This experience identified for our team both unique and heightened challenges in discussing goals of care. First, there is heightened emotion amongst family members and staff due to the fear and uncertainty surrounding this pandemic. Our social workers currently describe feeling "exhausted" by the intensity of emotion expressed by family members who cannot be at the bedside. Both for our own teams and all hospital staff members, we have tailored the Vital Talk Covid Communication Resources (1) to the hospital setting and are distributing it actively and widely. We are also mindful to practice and model self-care, describing at team huddle each morning, one positive change the pandemic has brought to our lives, such as spending more time with family. We also plan to delegate one person to collect and distribute important email notifications and try to avoid constant exposure to national news.

Second, the restrictions enacted to reduce the spread of this disease have significantly impaired communication with both patients and families. Medical teams are rotating more frequently than usual, as exposed providers are being sent home to quarantine. Using the

telephone, we are now acutely aware of our reliance on visual and body language cues to tailor these difficult conversations. In addition, we feel that the inability to use our body language to convey empathy has a negative impact on engendering trust. In order to manage situations where families can only be reached by phone, we have identified a single team member who can make contact with the family daily.

For phone conversations with both families and patients, we are developing a protocol which includes finding a quiet space to make the call, stating immediately that there is no emergency, and acknowledging the challenges of phone communication. Due to limits of phone-based communication, we are now acquiring the equipment and experimenting with platforms for video visits. For patients on the ventilator, we allow families to see the serious condition of the family member, as what they often remember from phone calls with staff is the ways in which the patient is "stable" (2). This is especially important, as families are remote when making the decision to transition to comfort care, in many cases not being allowed to come to the hospital to say their goodbyes.

A significant theme in the goals of care conversations with Mr. W's wife was hope. Normally, as experts in prognostication, our team would help family to reframe hope to a more realistic goal, but with this new illness information continues to be gathered, and trajectory is less clear. For this reason, our providers struggled with the uncertain urgency for re-addressing code status. To obtain the most up to date information, we are reviewing online resources such as MDCALC (3) and collecting relevant articles (4,5). It remains difficult to respond to the hope surrounding experimental treatments. What has helped our team, given that risk factors for mortality are age and comorbid conditions, is to separately assess morbidity and mortality from those factors alone. For Mr. W., even without the presence of COVID, the seriousness of his current condition points to a limited chance of survival with significant morbidity at best.

Recommendations for Action:

Triaging Goals of Care Conversations in Hospitalized Patients:

The first area of importance is to engage hospital leadership and understand their priorities. Palliative care teams may be asked to practice in their original specialty on the front lines, and leaders must be reminded of the critical role for palliative care specialists in this crisis. As consult volume may decrease initially, consider developing a strong presence in the Emergency Room to augment goals of care conversations at admission and identify patients that would benefit from a formal palliative care consult. We also suggest regular rounding in the ICU to support the staff and promote appropriate consultation. For hospitals who localize COVID suspected or positive patients, units can be contacted for support and solicitation of consults. Staff may need to be reminded that palliative care can provide remote consults through telephonic and video conferencing, especially if tablets can be dedicated to that unit. Palliative teams should continuously monitor need and develop a surge plan for staffing and prioritization which might include utilizing outpatient and community providers and creating a plan for 24/7 accessibility. Some team members may be able to work from home, decreasing hospital exposure and preserving the work force. If asked to provide front line hospital care, suggest admitting and managing patients who are on comfort care due to team expertise in symptom management.

Address the Potential for Limited Resources:

With the tragic experience of Italy in this pandemic, of great concern is the inability to supply needed resources such as ventilators. While the priority of many leaders is to obtain additional resources, the role of palliative care is to ensure patients are able to make informed decisions so that we are using these resources appropriately. Nevertheless, given the rate of spread of this illness, the need for resource rationing may be inevitable. As recommended by Dr. Diane Meier, palliative care can be part of the development of these standards, but should not be part of the rationing workforce. In addition, palliative care teams can develop scripting for intensivists for code status discussions and recommended intervals for reviewing goals of care. ICU teams may be concerned that performance of CPR will likely not benefit patients with progressive respiratory failure and risks exposing health care workers to this deadly disease. Providers and families alike need to be reminded that putting a DNR in place does not ensure patient death. As a matter of public health, states and institutions may want to revisit policies which do not allow two physicians to write a DNR order when CPR is medically inappropriate.

Proactively Engage in Goals of Care Conversations in the Community:

Finally, given the restrictions on visitors in hospitals and nursing homes, it is imperative that patients with poor chance of survival are given the chance to make an informed decision about remaining home. High risk patients can be identified such as patients in nursing homes, patients receiving palliative chemotherapy, and those with underlying cardiac and pulmonary conditions. Scripts can be generated using tools such as the COVID shared decision making tool by NHPCO (6). To perform these conversations, consider engaging hospice team members who may have less "windshield time" if they are restricted from visiting patients. Finally, identify a mechanism for delivery of completed advanced directives to isolated patients.

Palliative care can offer important solutions in this crisis, but the service will not be "business as usual." Teams need to be flexible and proactive in order to wade through intense emotion and promote difficult but critical discussions about goals of care. Palliative care leaders will have unique perspectives and priorities which need to be communicated to hospital and health system leadership. Innovative strategies and tools must be developed to minimize disease exposure and reach as many patients as possible before they develop critical illness.

The "silver lining" is that all of these efforts serve to enhance and promote what palliative care teams have already been striving for. The need for earlier goals of care conversations, multidisciplinary team work, and enhanced use of technology and telemedicine will not fade with the resolution of COVID-19. Let our call to action help us to maintain hope in the face of so much serious illness.

Table 1: Recommendations for Action

Triage goals of care consults in hospitalized patients	**Address the potential for Limited Resources**	**Proactively Engage in Goals of Care Conversations in the Community**
Cultivate strong presence in emergency room, ICU and	Advocate for policies at your institution addressing rationing	Develop a system to identify patients who are at high risk

COVID units	of scarce resources	for hospitalization
Develop surge plan for staffing and prioritization	Assist ICU leadership to develop scripting and timeframes for goals of care discussions	Develop a workforce and script to perform these virtual conversations
Utilize phone calls and telemedicine to minimize exposure	Review state and institutional policies surrounding DNR	Identify mechanism to complete advanced directives virtually in community

References:

1) COVID-Ready Communication Skills (https://www.vitaltalk.org/guides/covid-19-communication-skills/)
2) Palliative Care Public Service Announcement #4 (https://www.youtube.com/watch?v=MnM3PELOO7Y)
3) MDCalc (https://www.mdcalc.com/covid-19#nnt)
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5) Weiss P, Murdoch D. Clinical course and mortality risk of severe COVID-19. *The Lancet.* Published online March 17. 2020.
6) COVID Shared decision making tool (https://www.nhpco.org/wp-content/uploads/COVID-19-Shared-Decision-Making-Tool.pdf)