Journal Pre-proof

Beyond Traditional Advance Care Planning: Tailored Preparedness for COVID-19

Joanna S. Cavalier, MD, Jennifer M. Maguire, MD, Arif H. Kamal, MD, MBA, MHS

PII: S0885-3924(20)30706-5

DOI: https://doi.org/10.1016/j.jpainsymman.2020.08.020

Reference: JPS 10609

To appear in: *Journal of Pain and Symptom Management*

Received Date: 6 August 2020

Revised Date: 15 August 2020

Accepted Date: 18 August 2020

Please cite this article as: Cavalier JS, Maguire JM, Kamal AH, Beyond Traditional Advance Care Planning: Tailored Preparedness for COVID-19, *Journal of Pain and Symptom Management* (2020), doi: https://doi.org/10.1016/j.jpainsymman.2020.08.020.

Beyond Traditional Advance Care Planning: Tailored Preparedness for COVID-19

[1]Joanna S. Cavalier, MD

[2]Jennifer M. Maguire MD

[1]Arif H. Kamal, MD, MBA, MHS

[1]Duke University, Durham, NC 27710

[2]University of North Carolina – Chapel Hill, Chapel Hill, NC 27516

Word Count: 1003

Table: 1

References: 5

Corresponding Author:

Joanna S. Cavalier, MD

Duke University

Durham, NC 27710

704-604-4520

Joanna.Cavalier@duke.edu

There are no conflicts of interests to disclose.

Key Message : COVID-19 has drastically altered how we care for patients, necessitating a new model of advanced care planning tailored to the logistical and psychosocial challenges put forth by the pandemic. This article provides suggested phrases and questions for clinicians specific to the complications of COVID-19, facilitating disease-specific preparedness.

Keywords: COVID-19, novel coronavirus, advanced care planning, palliative care, disease-specific advanced care planning

Running Title: COVID-19 Disease-Specific Advance Care Planning

To the Editor,

At the time of writing, there have been over 18.6 million patients across the world with the novel coronavirus (COVID-19)(1). COVID-19 has drastically altered how we care for patients, requiring barriers between providers and patients that undermine the depth of conversations and the ability to keep patients and families truly informed. The pandemic has introduced both logistical and psychosocial challenges put forth by resource shortages, visitor restrictions, and requirements for social distancing. These challenges necessitate early, intentional conversations about preferences, values, and goals of care. This preparedness planning and documentation should address both general concerns and specific issues to the sequelae of COVID-19, allowing us to care for our patients in an informed and respectful manner.

Advanced care planning (ACP) helps discern patients' values and preferences regarding future medical care, allowing providers to treat patients with dignity in the face of decompensation, critical illness, and fragmented interactions. Personal protective equipment, lack of loved ones at bedside, and time limits on face-to-face interaction cause these ACP conversations to become disjointed and impersonal, particularly after patients have become severely ill. The presence of many layers of separation between patients and their providers requires deliberate, timely ACP specific to COVID-19 with clear documentation of preferences.

Traditionally, ACP focuses on either (1) eliciting patient preferences broadly or (2) a limited set of situations and prompts delineated in a document. For example, state-specific advance

directive forms may narrowly address cardiac resuscitation, artificial nutrition and hydration, and decision-making during loss of capacity. However, such documents may not address important issues specific to patient's condition, such as preferences regarding bowel obstruction management in advanced ovarian cancer, or mechanical pump failure for left ventricular assist devices placed for advanced heart failure. Given the unique challenges raised by COVID-19, we have seen that addressing broad issues remains important, but may miss specific, just-in-time questions pertinent to a potential impending clinical crisis.

To complement broader advance care planning, we propose the implementation of condition- and care transitions-specific preparedness planning for COVID-19. This approach, similar to pre-procedural informed consent, focuses patient-clinician conversations on the most salient areas of uncertainty and complexity related to a condition, disease, or care transition. Dissimilar to informed consent, the primary goal of preparedness planning is not necessarily to make a decision, but to establish a framework – shared by patients and understood by the clinical team – about how decisions should be made. Then, these specific preferences are documented in a preparedness plan separate from, but complementary to, general ACP documents. Such tailored preparedness planning has been shown to be effective in a number of conditions. For example, the use of disease-specific ACP in a heart failure population led these patients to more frequently state their personal treatment preferences, complete documentation of their health directives, and utilize hospice services. Moreover, disease-specific ACP is effective in aligning proxy decisions with patients' wishes (2). We must extend this approach to COVID-19, and ultimately to other pertinent health conditions, where providers need timely guidance from patients regarding how best to manage their care.

By focusing on the most common complications of COVID-19, we can support these patients through and beyond hospitalization. In one retrospective study of 52 COVID-19 critically ill patients, 62% had died at 28 days. 67% developed acute respiratory distress syndrome, 71% required mechanical ventilation, and 17% needed renal replacement therapy (3). Another case series demonstrated acute strokes in 5.7% of patients with severe infection (4). While the rate of post-intensive care syndrome is not yet known, we can extrapolate that those who survive an intensive care unit stay, particularly within the context of the pandemic, will suffer from physical complications, cognitive deficits, and mental health impairments. Thus, COVID-19 disease-specific preparedness planning may involve discussing preferences for mechanical ventilation, tracheostomy and percutaneous feeding for prolonged ventilation, hemodialysis (acute and chronic), and post-acute recovery issues.

Beyond the medical complications, navigating logistical and psychosocial complexities also requires assessment and planning. For all serious illnesses, identifying surrogate decision makers for health decisions is standard of care. Narrowed visitation policies, however, may require clinicians to dive deeper into preferences for individual contacts across a range of clinical outcomes. For example, a 72-year old with respiratory complications from COVID-19 is admitted to a hospital with a one-visitor policy. She might identify her husband as a surrogate decision maker (but prefer he stay at home due to increased personal risk of COVID-19), an adult child as the in-person hospital visitor, and a spiritual counselor as the sole visitor if the course worsens. The patient's clinical course may require a prolonged intensive care unit stay, and thus lead to a post-discharge rehabilitation period measured in months or longer in a facility

outside her home. This patient may avoid aggressive measures, such as long-term ventilation, if these measures will result in transfer to a facility that limits family, friend, and pet visitation due to COVID-19. As such, disease uncertainties coupled with evolving psychosocial barriers necessitate that clinicians address upfront both the general philosophies and relevant specifics.

Table 1 suggests specific questions and phrases to consider for a COVID-19 preparedness plan. We also propose further work in tailoring ACP documents to reflect COVID-19-specific planning. Future work should involve the development of standardized processes for performing COVID-19 preparedness planning alongside general ACP at the time of hospital admission, adapting current physician orders for treatment (e.g. Physician Orders for Life Sustaining Treatment), and developing population-health level intervention encouraging individuals to consider these questions prior to time of illness or admission.

COVID-19 can result in severe illness for anyone. Two-tiered ACP, addressing both general and COVID-19-specific assessments of preferences and values, allows patients, families, and providers to discuss overarching goals while planning for pertinent issues in the immediate future. It also allows for complementary but distinct documentation that provides a general roadmap alongside a situation-centered guide. By using both broad and tailored ACP for our patients with or at risk of severe infection, we can treat our patients in a dignified, respectful way that aligns with their wishes and priorities in this unprecedented time.

References

1. Conoravirus Disease (COVID-19) Dashboard [Internet]. World Health Organization. 2020 [cited 2020 Aug 6]. Available from: https://covid19.who.int/
2. Schellinger S, Sidebottom A, Briggs L. Disease specific advance care planning for heart failure patients: Implementation in a large health system. J Palliat Med. 2011;
3. Yang X, Yu Y, Xu J, Shu H, Xia J, Liu H, et al. Clinical course and outcomes of critically ill patients with SARS-CoV-2 pneumonia in Wuhan, China: a single-centered, retrospective, observational study. Lancet Respir Med. 2020;
4. Mao L, Jin H, Wang M, Hu Y, Chen S, He Q, et al. Neurologic Manifestations of Hospitalized Patients with Coronavirus Disease 2019 in Wuhan, China. JAMA Neurol. 2020;
5. VitalTalk. COVID Ready Communication Playbook [Internet]. VitalTalk COVID Resources. 2020 [cited 2020 Aug 6]. p. 1–12. Available from: https://www.vitaltalk.org/guides/covid-19-communication-skills/

Table 1: Common Complications in COVID-19 Patients and Advance Care Planning Phrases (5)

Complication	**Phrases & Questions**
Respiratory failure	Tell me what you understand about different types of breathing support. Are there types of support you would or would not want? Patients with COVID-19 often require the support of a breathing machine for a long time if the infection becomes severe. If this were to happen to you, what would you think? "Life support" means something different to everyone. What does this phrase mean to you? What sort of life support would you accept short-term and long-term?
Renal failure	This infection often causes damage to patients' kidneys, resulting in the need for us to support your body with something like dialysis. Is this something you have ever considered?

	Have you known anyone who was on dialysis in the community? What is your understanding of dialysis?
Stroke	Are there any activities or abilities that are so important to you, that you could not imagine life not being able to do them? Strokes can result in parts of your body not working normally, such as interfering with swallowing or talking. If that were to happen, what is the right way for us to care for you?
Death	Though we have limited treatments for this infection, unfortunately many people have died from COVID-19. I worry that if your infection becomes severe, you may die from this virus. What should I know about you to best care for you during this very serious illness? In the event that you become very ill and are unable to communicate your wishes to us, who is your health care decision maker? Have you spoken with him/her about your preferences? Many people have thought about where they would want to die, such as in their home or in a community hospice facility. Is this something you have ever thought about?
Lack of visitation	While we cannot allow visitors into the hospital, we can keep your loved ones updated via telephone. Who would like us to update on a daily basis?

	If only one person could come and visit you in the hospital or in a nursing facility, who would that be? Can you imagine any changes in how you are doing that would change that answer?
Post intensive care syndrome	After being cared for in the intensive care unit, most patients have to get used to new normal, different from their life prior to getting sick. What questions do you have about that? After leaving the intensive care unit, many patients are too weak or too sick to go back to the place they previously called home. In what ways does knowing this affect how you make medical decisions?
Post-acute care needs	With the risks of COVID-19, there may be limited options of where patients can rest and build their strength after leaving the hospital. Where is home and family for you? Any preferences we should know when considering your plan after leaving the hospital? After leaving the hospital, if the rehabilitation center limited in-person visitation, how would you prefer to communicate with others? If your situation worsened where a visit back to the emergency department and possible hospitalization was considered, what would you think?