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Never Waste a Pandemic: Strategies to Increase Advance Care Planning Now

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Coronavirus disease 2019 (COVID-19)—related deaths and hospitalizations have created a global health crisis with unprecedented scarcity of health care resources and staffing in parts of the United States and around the world. The pandemic has led to important discussions about just allocation of health care resources. News headlines about COVID-19 feature family members who announce hospitalized loved ones died after treatment options were denied. Other articles demonstrate that patients may not fully understand the ramifications of elected care in an intensive care setting, unpredictability of outcomes, and how this may impact future abilities.[1] Between the realities and perceptions of living and dying in this pandemic, COVID-19 has spotlighted the critical role of upstream conversations between health care workers and patients to help align medical care with the goals and values of the individual — what is referred to as advance care planning (ACP). Although ACP has an established precedence in health care, commonly it has been limited to elderly patients or those with serious illnesses. Although COVID-19 has hit the geriatric population the hardest, the pandemic has made ACP conversations relevant for younger and even previously healthy patients with associated hospitalizations and deaths. The shared experience of the COVID-19 pandemic is an opportunity to shape public discourse about ACP and help develop system practices that regularly use ACP to learn more about individual patient wishes, values, and treatment plans.[2]

This article aims to facilitate upstream discussions for value-concordant health care during this and future pandemics or health care crises. Accordingly, we highlight three strategies to increase ACP patient conversations urgently: 1) Redefine success as simply initiating an ACP discussion — learning about patients' values, goals, and priorities is an achievement by itself; 2) Address patient and health care worker emotions about ACP through timely resources and individual or group trainings; and 3) Normalize ACP discussions through omnipresent and team-based approaches, so that patients may feel less targeted or threatened by these conversations.

REDEFINE SUCCESSFUL ACP DISCUSSIONS

Culturally, health care workers view an ACP discussion as successful when patients explicitly choose a clinical course (e.g. hospitalization, re-hospitalization, resuscitation, palliative care or hospice). Using this approach, patients may choose code status and treatment interventions without alignment with their established values and amidst an acute crisis. We redefine success as health care workers initiating discussions with patients about their health care values before a crisis occurs and in advance of hospitalizations. In effect, this means less emphasis on discrete decision-making, such as "getting the code status." Instead, the key step is to learn in advance about patient values, goals, and priorities, which often become more salient during life-threatening illness. This approach fits the traditional model of history-taking before clinical decision-making and may yield more robust clinical-decision making for the patient, family, and entire health care team in the future.

A brief description about patient wishes in the medical record can assist health care teams and reassure family members that the health care team will follow the documented wishes of the incapacitated patient. Ideally, brief ACP documentation is centralized in the medical record for easier reference.

Patients and family members often make overwhelming and technical decisions about code status and treatment plans under the

stress of a hospitalization. Outpatient ACP discussions may help patients translate personal anecdotes and align values with options for medical care more effectively over time. As patients describe these values, health care workers can realize the patient's goals within the context of their health state and prognosis.[3,4] Patients commonly choose from a menu of advanced medical options (eg, hospitalization, resuscitation, intubation, dialysis). In the outpatient setting, health care workers can support patient autonomy through informed conversations about potential outcomes to synchorize with the priorities of the patient. Discussions that focus on patient values, hopes, fears, and worries can create the big picture of what is important to the patient. This can become the foundation for meaningful health care plans for the health care team and patient. Toward these goals, health care workers can use the Serious Illness Conversation Guide[5] and other validated resources directly, even verbatim, to develop more congruent, patient-centered, value-driven plans. This allows for better alignment of treatment considerations with patient values and to plant seeds towards future discussions.

ADDRESS EMOTION

COVID-19 deaths in previously healthy people have demonstrated that all patients benefit from upstream ACP discussions. However, there are several well-characterized barriers to ACP discussions: unclear best approach, limited time, and fear of unpopular patient-family responses.[6] Commonly, ACP discussions can elicit emotion for patients and health care workers alike, which may trigger avoidance.[6] As an additional amplifier of mistrust, inpatient ACP conversations occur under distress, where emotions run high and time is of the essence. To address these challenges, health care workers can lessen their own expectation of the outcome through the redefinition of ACP discussions, promote patient storytelling for relevant examples of their priorities, and expect emotion as normal with use of existing resources (Table).

Health care workers may create better patient experiences through the message: "I am here to learn more about what you value" and with less direct emphasis on discrete decision-making or code status discussions.

Shortcuts towards code status decisions may relate to multiple and untimely code status and unfortunate incongruencies for the patient. Instead, health care workers can encourage sharing of the experiences of patients' loved ones in end-of-life care and impact on their own priorities.

The unpredictability of patient responses may increase anxiety of health care workers with less ACP engagement. However, skills to address emotion often grow with experience and dedicated practice, and this is relevant in a variety of contexts. Health care workers can do this by building ACP discussions into routine patient appointments ubiquitously with use of several available resources (Table).[5] Health care systems can look for opportunities to provide training and resources for staff on ACP and emotion-handling to augment the skills of the entire team.

ACP discussions may trigger feelings of fear and mistrust, amplified within vulnerable populations in our community. Although ACP conversations cannot resolve longstanding, systemic discrimination, discussions that are frequent and iterative may prioritize patient values, bridge gaps in health literacy, increase understanding of individual and community resources, identify critical surrogate decision-makers, and help clarify end-of-life preferences.[7,8] To improve cultural sensitivity, heath care workers can apply inclusive language and standardized ACP tools. The Table provides explicit step-by-step patient-tested tools to facilitate ACP within the context of cultural responsiveness. Akin to learning to formulate a differential diagnosis in medical education, skill development in cultural responsiveness and communication require dedicated practice for greater comfort and proficiency. Local palliative specialists and geriatricians may be helpful resources for feedback on challenging situations. Health care workers can reduce heightened emotions with the familiar goal of building thoughtful patient relationships through ACP discussions.

NORMALIZE ACP DISCUSSIONS

Given this enormous task, palliative care health care workers and geriatricians across the country have stepped up ACP efforts, targeting highest risk groups.[9] Health care

TABLE. Strategies to Improve Advance Care Planning

Strategies to launch ACP discussion	Action steps for health care workers in multiple levels	Resources
Redefine success Redefine success as having an upstream conversation about patient values, rather than making specific patient decisions. ACP discussions themselves can build patient rapport and trust. A sentence in the medical record about activities, relationships, and capabilities that are important to the patient can form a springboard for meaningful ACP. Ideally, documentation is centralized for easy review by health care teams.	**Individual** Choose an ACP discussion tool that seems most natural to you and use part or all of it with a patient or family member over the next week. **System** Set benchmark goals with team or population to increase ACP discussions and documentation of surrogate decision makers. **Population** Collaborate with community partners to help patients engage in documenting values and surrogate decision makers.	Communication tools and talking maps The Serious Illness Care Program's COVID-19 Response Toolkit: includes versions of the Serious Illness Conversation Guide for different care settings and populations: https://covid19.ariadnelabs.org/serious-illness-care-program-covid-19-response-toolkit/ VitalTalk's COVID-ready Communication Playbook: https://www.vitaltalk.org/guides/covid-19-communication-skills/ Other communication resources[7] https://www.uptodate.com/contents/discussing-goals-of-care http://conversationsofalifetime.org/provider-info/ For patients and families Online toolkits and websites for ACP https://prepareforyourcare.org Advance Directives in English and Spanish across the U.S., including engaging, evidence-based, ACP guide and personal videos https://theconversationproject.org/ Written conversation guides in multiple languages for inclusive patient discussions of wishes in end-of-life care https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/ Universal Durable Power of Attorney forms for all 50 states https://www.cdc.gov/aging/pdf/acp-resources-public.pdf Resources to assist with ACP, palliative care and hospice, caregiving, cognitive impairment, and legal issues Summary resources for cultural responsiveness https://www.uptodate.com/contents/cross-cultural-care-and-communication?sectionName=Sexual%20and%20gender%20issues&search=cultural%20palliative%20care&topicRef=86305&anchor=H15&source=see_link#H15 Cross-cultural care and communication tips https://www.capc.org/covid-19/communication-skills-bridging-inequality-during-covid-19-pandemic/ Communication tools to improve health care worker engagement for more equitable care
Address emotion Emotions are a normal part of conversations about values and decision making. Included resources describe tools and strategies for responding to patients' emotions so that they feel heard and are better able to process information and make decisions.	**Individual** Expect emotions in conversations and practice using emotion-response tools (practice with friends and family, too). **System** Use team-based approach to support both team and patient/family emotions.	

TABLE. Continued		
Strategies to launch ACP discussion	Action steps for health care workers in multiple levels	Resources
	Population Encourage diverse community and public-facing messages to normalize ACP discussions and emotional responses.	
Normalize ACP discussions COVID-19 helps to normalize the timeliness and generalizability of these discussions. This can be a way to introduce ACP discussions and potentially mitigate concerns by targeted populations.	**Individual** Set improvement goal for number of ACP discussions within patient population. **System** Develop team-based approach to engage ACP discussions. Promote signage and brochures in patient areas to promote patient-led discussions. **Population** Encourage all health care communities, public health agencies, and community partners to put forward public-facing messages to promote ACP discussions with patients.	

ACP, advance care practice; COVID-19, coronavirus disease 2019.

systems, communities, public health agencies, and community partners can further increase the accessibility of ACP discussions through public-facing, multimedia messages. These campaigns may reduce public anxiety and distrust through widespread promotion, and directly encourage all patients to launch ACP topics with health care worker and family members.[8] Public-facing messages can show ACP interactions with health care teams and review the evolution of clinical plans with waning and even less predictable disease states (eg, discussion of COVID-19 deaths by age group and survival rates after codes or prolonged intubation). When located in public and common patient care areas, signs and brochures with thoughtful ACP messages may yield same day patient discussions with health care workers. Websites and social media forums may assist with patient questions and improve informed patient decision-making. Public-facing messages can influence patient perception of ACP — including younger and healthier patients — as a priority topic to explore values during outpatient appointments and in advance of potential crises.

Standardized and interactive approaches can increase ACP discussion frequency for normalization. Collaborative interdisciplinary and interprofessional teams can help ubiquity, cohesion, and timeliness (ie, nurse documents patient values while physician explores values, prognosis, and evolving plans). Patient discussions about prognosis preferably includes input from subspecialists with evolving conversation about personal priorities within the projected timeframe. Existing ACP approaches and resources can make it easier for health care workers to streamline these conversations and address expected emotion (Table).[5,8] In short, health care systems and agencies can promote ACP as inherent to healthcare planning both during and beyond this COVID-19 pandemic.

CONCLUSION AND NEXT STEPS

The pervasiveness of COVID-19−related illness and deaths across age groups has required vast

efforts in goals of care conversations in a time of crisis. The COVID-19 pandemic demonstrates the importance of everyone working collaboratively to promote ACP efforts with no time to waste. It is important to build upon the important lessons of this pandemic to prepare for possible resurgence with new strains, future disasters, or pandemics.

Critically, all primary care health care workers and subspecialists must continue to engage patients in ACP discussions. Optimal discussions explicate patient values, identify surrogates for decision-making, and take place in advance of patient hospitalization for greater congruency of the health care plan. This is best done through systems that encourage discussions as an interprofessional health care team.

Through the unfortunate shared experience of COVID-19, ACP discussions have become more urgent and relevant to all patients. During this time, individual health care workers can build upon their ACP skills while health care and public health systems can normalize and promote efficient ACP practices. We challenge readers to work within their sphere of influence to propagate a multilevel wave of ACP discussions across the country:

1) Individual level — Over the next week, choose one ACP discussion tool and use part or all of it with a patient or family member; seek feedback from local palliative or geriatric specialists when helpful.
2) Systems level — Develop approaches within health care teams to launch more ACP discussions with centralized documentation.
3) Population level — Implement public-facing campaigns to normalize ACP discussions for all patients.

Never waste a pandemic — the time to act is now!

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REFERENCES

1. Hashem MD, Nallangangula A, Nalamalapu S, et al. Patient outcomes after critical illness: a systematic review of qualitative studies following hospital discharge. *Crit Care*. 2016;20(1):345.
2. Kaufman SR, Shim JK, Russ AJ. Revisiting the biomedicalization of aging: clinical trends and ethical challenges. *Gerontologist*. 2004; 44(6):731-738.
3. Block BL, Smith AK, Sudore RL. During COVID-19, outpatient advance care planning is imperative: we need all hands on deck. *J Am Geriatr Soc*. 2020;68(7):1395-1397.
4. McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: what do we know and we do we go? A scoping review. *J Am Geriatr Soc*. 2020; 69(1):234-244.
5. Bernacki R, Paladino J, Neville BA, et al. Effect of the serious illness care program in outpatient oncology: a cluster randomized clinical trial. *JAMA Int Med*. 2019;179(6):751-759.
6. De Vleminck A, Houttekier D, Pardon K, et al. Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review. *Scand J Prim Health Care*. 2013;31(4): 215-226.
7. Carey EC, Sadighian MJ, Koenig BA, Sudore RL. Cultural aspects of palliative care. In: UpToDate, Givens J (Ed). Waltham, MA; 2019. https://www.uptodate.com/contents/cultural-aspects-of-palliative-care?search=Cultural%20aspects%20of%20palliative%20care&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1. Accessed August 25, 2021.
8. Sudore RL, Schillinger D, Katen MT, et al. Engaging diverse English- and Spanish-speaking older adults in advance care planning: the PREPARE randomized clinical trial. *JAMA Intern Med*. 2018; 178(12):1616-1625.
9. Nakagawa S, Berlin A, Widera E, Periyakoil VS, Smith AK, Blinderman CD. Pandemic palliative care consultations spanning state and institutional borders. *J Am Geriatr Soc*. 2020;68(8): 1683-1685.