Special Article

Colorado Palliative Care and Hospice Crisis Standards: Moving Beyond Critical Care Planning

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Abstract

Palliative care (PC) and hospice services have experienced shortages before 2020, and during the initial phases of the current pandemic, more critical gaps are expected with future surges, much as scarcity in intensive care unit services may recur during the COVID-19 pandemic. Although ethical allocation of ventilators and intensive care unit care is the subject of important discussions during this pandemic, caring for those at the end of life and those not desiring or qualifying for critical interventions must not be neglected, as critical care and comfort-focused care are intertwined. We review state and regional gaps already recognized in planning for scarcity in PC and hospice services during this pandemic and describe the planning initiatives Colorado has developed to address potential scarcities for this vulnerable and diverse group of people. We hope to encourage other state and regional groups to anticipate needs in the coming surges of this pandemic or in public health crises to come. Such planning is key to avoid the degradation of care that may result if it is necessary to invoke crisis standards of care and ration these essential services to our communities.   J Pain Symptom Manage 2021;■:■−■. © 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Message

This article describes the Colorado planning initiative directed at needed planning for contingency and crisis standards to assure appropriate palliative care and hospice services in the context of the COVID-19 pandemic.

Introduction

During a disaster or pandemic, as in usual times, every attempt should be made to align treatment delivered to patients with the care they desire, particularly near the end of life. Some persons may want hospitalization and critical care interventions, whereas others may prefer comfort-oriented care in their home or community residences. In addition, some patients under crisis standard conditions may not be eligible for critical care therapies or may not respond to a trial of aggressive treatments. Palliative medicine providers are uniquely positioned to help provide care for patients and their families across the spectrum of serious illness, including for those who still seek aggressive treatments, whereas hospice providers have unparalleled expertise in providing comfort and support to patients nearing their end of life. Hospice specialists particularly practice in a multitude of care settings in their community, including traditional residences, nursing homes, and inpatient hospice units. Both

services are critical components of health care for patients during normal times and the pandemic, though workforce shortages have been reported even before the stress of the 2020 pandemic.[1,2]

Conventional palliative care (PC) and hospice systems have been strained beyond usual capacity during this pandemic already.[3,4] These stresses may limit access to high quality, comprehensive support for both seriously ill and dying patients. Gaps in PC and hospice support across settings may also impede timely transitions to quality home-based or community-based care, a phenomenon that impacts the care of patients across the entire system and potentially exacerbates hospital overload. It is imperative across all components of the system—both inpatient and community settings—that we proactively implement measures to mitigate barriers to the provision of the best PC and hospice services possible to all patients who may need these services. Table 1 outlines critical steps to identifying and implementing expanded hospice and palliative medicine (HPM) needs during crisis conditions, which we further describe below.

Overview and Rationale: A Review of Existing Plans

The concept of "crisis standards of care" (CSC) is not new. Nonstandard medical care occurs during times of war and during massive natural disasters. Organized thinking about the impact of such disasters on our healthcare system is several decades old. Beginning in the early 1990's, such efforts culminated in a seminal conference hosted in August 2004 by the HHS Agency for Healthcare Research and Quality, resulting in a White Paper: Altered Standards of Care in Mass Casualty Events.[5] This was followed by multiple other publications, both as monographs and journal articles, on this and related topics. The ever-present threat of pandemic influenza encouraged many public health and medical professionals to highlight potential ventilator and intensive care unit (ICU) bed scarcity during a pandemic. A significant advance in the area of CSC was the publication of the 2012 Institute of Medicine's (IOM) *Crisis Standards of Care: A Systems Framework for Catastrophic Disaster Response.*[6] This seven-volume work covers CSCs as they relate to hospitals, emergency medical services, alternate care systems, state and local governments, and legal aspects of care. Ethics, mental health, and PC are discussed in Volume 1 as cross-cutting themes. According to this seminal work, "PC in the context of a disaster with scarce resources can be considered a moral imperative of a humane society."[6] The extensive discussion includes a listing of the essential elements of PC under crisis conditions, as outlined in Table 1 of that document.[6]

Table 1
Critical Planning Steps: An Outline to Action

Critical Planning Steps: An Outline to Action	
Review Published Plans & Lessons from Early Experiences	• The IOM 2012 outline that provides specific guidance for palliative care planning.[6] • State or regional CSCs plans that identify HPM needs.[8,10–12] • Early reports of 2020 HPM experiences.[3,9]
Determine HPM Goals	• Identify similarities and differences between critical care and HPM disaster goals in your healthcare systems.
Identify Actionable Gaps	• Convene stakeholders with wide professional and regional representation. • Determine HPM services which may become or are already scarce in these areas: - Staff - Stuff (Resources) - Space - Support
Create an Action Plan	• Educate government, medical and public health officials with wide regional representation in HPM principles and potential gaps, to ensure equitable and appropriate delivery of HPM resources across healthcare systems • Present to community leadership and disaster Operation Center leadership. • Negotiate and allocate responsibilities among with Command Center, Health Dept, Medical Society, Long-term Care leadership, and other influencers throughout region.

CSC = crisis standards of care; HPM = hospice and palliative medicine; IOM = Institute of Medicine.

Based on size or duration, a disaster may progress from conventional care (where normally expected care can be provided) to contingency care (where care is essentially normal although through nonstandard approaches in some cases) to crisis care. This final category is characterized by overwhelming demands on healthcare delivery, which may manifest as shortages of personnel, medications, supplies, space, or other essential elements of care. When planning for disasters, it is helpful to designate specific triggers which indicate having to move from one category to another.

This pandemic is caused by a novel virus, resulting in treatment and prognostic uncertainties:

• Significant spreading may occur by infected but asymptomatic or presymptomatic individuals,

- making quarantine and contact tracing much more difficult.
- The wide variability in the presentation of the disease allows some individuals to dismiss the potential severity of infection and consequently forego proven good public health practices (physical distancing, mask wearing, hand washing, etc).
- The morbidity and mortality of the infection increases significantly through each decade of life above middle age; yet, the significant morbidity and mortality for younger people seems underrecognized by the general public.
- This pandemic has posed an ongoing stress to healthcare systems and continues to wax and wane in different geographical locations over time.

Goals for Palliative Care and Hospice in a Pandemic

Guiding principles for allocating resources in times of scarcity differ for patients requiring PC and hospice services from principles for allocating resources such as ventilators or ICU beds. In the latter, priorities are placed on saving the most lives or life-years. In the former, the foundational principle is minimizing human suffering across the healthcare system, including suffering of patients, families, providers, or communities.

The range of persons that would benefit from HPM services in a crisis or pandemic is broad. It encompasses patients with needs in home, clinic, hospital, ICU, and long-term care (LTC) settings, as well as families, caregivers, and healthcare team members. Examples of PC and hospice management and support needs include patients with:

- unknown or unclear goals of care;
- refractory symptoms or other physical, emotional, or spiritual distress;
- decisions to forego hospital admission, opting for comfort-focused measures and symptom management in place;
- inability to discharge from the hospital because of unsafe or inadequate home support or limited bed availability;
- barriers to admission to a LTC facility with suspected or documented COVID-19 infection because of the risk to current residents;

As well as patients, family and caregivers who need:

- management and support when patients lack access to mechanical ventilation or ICU care because of CSC-invoked triage decisions;
- advice and support, practical, emotional, or spiritual, while caring for loved ones with serious or life-threatening illness;

- support coping with loss and grief following the death of a loved one;
- assistance after death at home when emergency medical system providers decline transport during crisis conditions.

Additionally, quality hospice care is critical for all patients requiring end-of-life (EOL) support, with or without a COVID-19 diagnosis. And providers and staff across all settings also need PC or hospice team expertise and support, including information, knowledge and skills, and emotional support to cope with moral distress, loss, grief, and bereavement.

Gaps in Palliative Care and Hospice Planning on a National Level

The need for PC and hospice service planning has been recognized in the past but mainly in relation to single-event disasters with overwhelming numbers of casualties.[6,7] As noted above, PC needs were included in the comprehensive IOM report of 2012. State-based CSC plans exist online for 34 states, according to a May 2020 review by the National Hospice and Palliative Care Organization.[8] However, despite the previous calls for PC planning, most state plans currently contain only brief mention of the importance of PC and hospice services as alternative pathways to critical care treatment. And such plans mainly focus on patients for whom critical care interventions are ineffective or when patients do not have access to critical care interventions as part of crisis triage algorithms, not including those patients who are already on a palliative or hospice trajectory. In a March 2020 survey of 73 acute care medical institutions with linked academic bioethics programs, only 26 had ventilator triage policies, and 23 of those 26 policies did recommend providing PC when resources were withheld or withdrawn. Policies on unilateral "do not resuscitate" orders were rarely addressed and inconsistent among those institutions, an omission also noted in the early New York City experience of PC specialists.[3,9] Aside from the Colorado initiative described here, planning for those who choose to focus on comfort or who need access to hospice services are only addressed in a meaningful fashion in the Minnesota crisis plans.[10,11] It is clear that such planning is at best inadequate to the current circumstances and needs.

The Colorado Initiative: Creating Action Plan

In March 2020, as COVID-19 cases began rising in Colorado, 15 ethics members and stakeholder clinicians from Denver Health Medical Center, the Center of Bioethics and Humanities at the University of

Colorado School of Medicine and National Jewish Hospital in Denver, Colorado, convened an ad hoc virtual ethics meeting to discuss concerns related to the potential need to triage ventilators and ICU beds for an anticipated surge of patients critically ill with COVID-19. Overarching concerns that were important for the State of Colorado were discussed, including:

- consistency, fairness, and transparency among all of our hospitals in Colorado,
- the vital nature of community involvement in this process,
- the importance of sharing resources, challenges, and solutions among institutions in Colorado, and
- a process to consider new challenges with ethical implications as the pandemic evolved.

These concerns were forwarded to the Colorado Department of Public Health and Environment, and the following day the chief medical officer of the Colorado Department of Public Health and Environment joined in the call along with several ethicists and clinicians from new institutions and cities in Colorado who shared these concerns. Over the next month, a grassroots working group of 135 people from 45 institutions and organizations and 16 cities in Colorado formed to address these concerns. A subject matter expert subgroup, convened by the long-standing Governor's Expert Emergency Epidemic Response Committee, started working on an updated Crisis Standard of Care for hospital triage in Colorado and assisting in community engagement around this process.

Colorado's disaster plans in past years focused on natural or man-made events and on possible time-limited infectious disease pandemics. In this year's situation, crisis planning started with anticipated critical care shortages in our state, as did planning in most other states. However, a group of clinicians and ethicists here recognized that the complexities we were facing were broader and needed further analysis and an action plan. Within this grassroots group of interested stakeholders, a group focused on HPM needs quickly evolved, recognizing that areas of potential scarcity in the many settings in which PC and hospice services are delivered required special attention.

The critical planning steps outlined in Table 1 primed this group to develop a plan to provide respectful care for hospice patients and the wide spectrum of patients needing PC support. The 2012 IOM report about disaster planning and response outlined categories at risk of scarcity: staff, stuff, and space.[6] Others have also highlighted the roles of PC in an epidemic or pandemic, both in this country and overseas.[12−14] More often, the poor integration of PC into pandemic oversight has been described.[3,15] As the Colorado group began to outline needs in the face of this particular pandemic, we added the critical category of "support" to these other three, given the interdisciplinary and family centered commitment of PC. Table 2 outlines the potential gaps and resource needs we identified and the proposed action strategies that would be important to planning before reaching crisis stages.

Staff: Palliative Care- or Hospice-Trained Personnel

The pool of specialists who deliver the comprehensive support, i.e., the hallmark of PC and hospice services was inadequate before the pandemic.[1,2,16,17] Demand for PC expertise in goals of care conversations and in complex symptom management has already overwhelmed specialist services in the early pandemic experience. Some strategies for augmenting these specialty skills have been reported.[4,18,19] Tools to help primary care providers who are not as familiar with EOL conversations and care are being disseminated nationally.[20-23] In New York City, a regional 24/7 Hotline was developed to answer the surge in demand for expertise in goals-of-care conversations more efficiently, and volunteer faculty was recruited to supplement PC specialists within the system at the peak of the surge.[18] Virtual telehealth consultation on inpatients and proactive identification of admitted patients who may have PC needs have also been used to expand the reach and efficiency of PC specialists.[19,24]

As outlined in the Table, it is also important to designate PC specialists (including medical social workers, nurses, physicians, advanced practice providers, chaplains, and volunteers) as essential caregivers to critically ill and dying patients, overcoming facility restrictions to access that have been reported in acute care hospitals as well as long-term facilities.[25,26] In Colorado, this has been particularly evident in LTC facilities, where hospice staff has been blocked from access for a multitude of reasons, including insufficient personal protective equipment (PPE), inadequate testing procedures, and failure to recognize their support as essential to the care of hospice patients within those facilities. Lack of leadership on a state and federal level has contributed to an inability for LTC institutions to understand the best and most up-to-date information on exposure protocols and testing risks, and this has caused marked variability in policies for multidisciplinary access.

Stuff: Critical Supplies and Other Resources

Inventorying resources ("stuff") is central to the duty to plan but particularly difficult when considering that PC and hospice services are provided across sites which range from the ICU through LTC facilities and patient homes. The variety of medications, PPE, equipment, testing materials, and electronic devices

Table 2
Palliative Care and Hospice Services: Potential Gaps and Required Actions in the Pandemic

Identified GAP	Required Actions
STAFF: Palliative care- or hospice-trained personnel	
Inadequate consultant access by specialist PC and hospice providers for patients in isolation in multiple sites.	• Institute executive action to designate palliative care (PC) specialists (including social work, nursing, chaplains, and volunteers) as essential caregivers.
Shortage of PC and hospice providers and/or staff (with little ability to flex) because of increased system demand across hospitals, LTC facilities, community providers, integrated systems, and hospice organizations.	• Develop regional 24/7 call center or virtual telehealth systems for access to PC and hospice specialists to deliver remote advice regarding end-of-life communication, family support, and pain/ symptom management where needed. • Identify regional resources to facilitate telehealth and specialty consultation access across systems and provide infrastructure for communication. • Assure liability protection for provider-to-provider consultation.
STUFF (RESOURCES): Critical supplies & other resources	
Shortage of adequate pain and symptom management medications, including IV and liquid opioids, sedatives, and other drugs needed to assure comfort in both inpatient and community settings.	• Develop and maintain continuous inventory and usage tracking tools to identify regional and state supplies in all sites. • Promote, mandate, and require sharing and transfer of controlled substances across organizations and communities to maintain continuity of care. • Update regulations to allow scheduled drugs (e.g., sedatives) to be administered at overflow sites. • Create pharmacy specialist consultation group to develop algorithms for alternative symptom-focused medications, including restricted drugs.
Limited access to symptom management medications in the home.	• Establish outpatient and ambulatory care processes to identify outpatient sources to support patients needing symptom management at home.
Shortage of other essential equipment necessary to assure comfort in place during a pandemic or other disaster.	• State/regional inventory and track of essential equipment, e.g., oxygen, pulse oximetry monitors, hospital beds, (at organizational, community, and/or state level) among LTC facilities, hospice care, and medical supply centers. • Require sharing of essential equipment across suppliers and organizations.
Shortage of adequate PPE to protect staff, patients, and	• Inventory and track essential PPE (at organizational,

(*Continued*)

Table 2
Continued

Identified GAP	Required Actions
families during a pandemic or other disaster.	community, and/or state level) among LTC facilities and hospices. • Require PPE sharing across organizations, institutions, hospices, and communities in accordance with PPE CSC guidelines. • Provide virtual education and support for lay persons to deliver safe home symptom management and care.
Lack of adequate and reliable testing to identify active and resolved infections to preserve and protect specialty-trained staff.	• Prioritize testing of personnel and families to allow adequate care for patients dying, with or without COVID- 19. • Shift testing resources from lower priority outpatient settings to institutions caring for patients requiring comfort-focused care.
Insufficient equipment or training to facilitate virtual ACP and other communication with patients/families at home or in other facilities.	• Assure adequate equipment and training for virtual communication in institutions. • Leadership affirmation of importance of virtual access to all institutions where ACP and end-of-life communications may occur and physical access near end of life for all patients.
SPACE: Facilities, beds, and other equipment	
Inadequate access to beds for all seriously ill patients who need symptom management and comfort- focused support across settings.	• Inventory community facilities and designate additional comfort-focused beds/units (COVID and non-COVID). • Locate options for alternative care sites with adequate beds, resources and visitation policies to provide quality end-of-life care. • Address policy barriers to licensing and staffing under specified surge conditions. • Obtain authorization for administration of essential palliative care medicines (i.e., opioids and sedatives) at alternate sites.
SUPPORT: Palliative care and hospice training in communication and symptom management skills	
Inadequate system- and community-wide advance care planning conversations and documentation of ADs, especially MDPOA and POLST documents.	• Postguidance tools for provider-initiated conversations in residential facilities to elicit or update documentation of agent with MDPOA and POLST-paradigm forms when appropriate. • Encourage virtual and in-person discussions by primary and specialty clinic

(*Continued*)

Table 2
Continued

Identified GAP	Required Actions
	sites and post tools or links to guide conversations.
	• Encourage hospitals and other facilities to review advance directives, esp. MDPOA and POLST-paradigm forms on admission and with changes in health status.
	• Develop early ACP planning conversation campaigns within communities with lay facilitators.
Gaps in symptom management skills by usual care providers	• Develop short on-line specialist-conducted education modules targeted to usual care providers, and links to best practice tools.
Regulatory barriers to the acceptance of verbal, electronic, or copies of AD documents when in-person signing of documents not safe or possible.	• Declare scope of legally acceptable documentation of conversations about ADs such as MDPOAs, including authorizing electronic signatures, "marks", or other methods of safely signing documents.
	• Accelerate development of electronic AD registries accessible across all care sites.
Inadequate psychosocial, emotional, and spiritual support for staff across settings.	• Post links to resources such as VitalTalk ™ or CAPC for front line staff to support difficult conversations and allay staff and patient distress.
	• Develop counseling services to help with moral distress of front-line providers.
Patient physical and social isolation, often without access to family/loved ones in hospital, residential, or home settings.	• Consider visitor policies to authorize chaplains, volunteers, or other palliative care and hospice support staff as well as loved ones to access patients in hospice or who are dying, with adequate PPE.
	• Develop compassionate visit guidance to include provisions for: - a decline in overall status because of worsening mental health - memory or cognitive conditions - progressively worsening conditions of grief and/or depression, confusion, anxiety - physical decline because of COVID-19 isolation restrictions.

ACP = advance care planning; AD = advance directives; CAPC = Center to Advance Palliative Care; CSC = crisis standards of care; LTC = long-term care; MDPOA = Medical Durable Power of Attorney; POLST = Physician Orders for Life-Sustaining Treatment (state-based from national paradigm); PPE = personal protective equipment.

for communication with families and surrogates adds to the complexity. Ensuring access to essential medications to address symptoms and to relieve suffering is critical.[27–29] World-wide, opioid shortages for palliative pain control have been reported during previous disasters.[30] Already during this pandemic, shortages have been reported for injectable opiates, antipsychotics, anxiolytics, corticosteroids, nebulized respiratory medications, metered dose inhalers, and even oxygen.[27] Also needing consideration are patients already receiving drugs for chronic conditions, as well as the current and increased demand for so-called "comfort" medications needed for caregivers to manage EOL care.[31]

Essential equipment also includes PPE, testing materials, pulse oximetry monitors, and hospital beds for all sites. In New York City, inadequate stockpiles of sedatives and pain medications have been reported.[3] In the early surge in Italy, hospices reported a lack of PPE.[15] This continues to be reported in skilled nursing facilities in the United States.[32-35] PPE shortages have been reported fairly regularly over the past summer in Colorado in some LTC facilities as well as hospitals and have triggered focused adoption of Crisis Standards for PPE. Shortages of testing materials have seriously hampered delivery of hospice services and PC support, limiting visitation and leading to deaths in isolation.[36] Only a regional disaster authority or state health department can require the necessary inventory information and sharing of essential equipment across suppliers and organizations; cooperation across organizations, institutions, hospices, and communities must occur in accordance with CSC guidelines. Colorado, even under the state's emergency disaster order, has struggled to inventory drug supplies or potential needs because of the wide variety of entities involved in attempts to assess.

Space: Facilities, Beds, and Other Equipment

Planning for a surge in demand for beds to care for patients with palliative and hospice needs is challenging because predicting what part of the healthcare system will be overwhelmed is difficult. Convalescent and rehabilitation overflow needs differ from comfort-focused or EOL needs.[37] One solution is establishment of alternative care sites (ACSs) with the ability to provide flexible configurations. Federal Emergency Management Agency describes three models: acute care sites to address critical care overflow patients; hospital care sites offering overflow for a full spectrum of patients, including those with uncertain prognoses; and nonacute or postacute care sites.[38] Another alternative might be expansion of hospice

care beds in LTC facilities, though this is often limited because sites may have COVID-19 restrictions and staffing shortages.[25,39] Massachusetts has described the suffering caused in trying to shift nursing home patients to COVID-specific sites, with confusion and gaps in continuity of care.[40] We found in Colorado that the planned ACSs were not designed to deliver general inpatient hospice or EOL care. Practical barriers needing solutions include access to parenteral opioids for breathlessness and pain; other symptom management medications; visitor regulations; nursing ratios; and virtual access infrastructure for families and for PC consultation. Planning for rural areas should consider that patients near the end of life with intensive treatment needs might be better prioritized to remain in acute care institutions, with ACS planning for convalescent recovering patients.

Support: Palliative and Hospice Training in Communication and Symptom Management Skills

As a specialty, one important core contribution of PC is comprehensive support: for patients to clarify goals of care, providers to feel comfortable managing symptoms, and patients, families, and care providers to receive grief and bereavement support. Multiple authors have pointed these needs out in the context of this pandemic.[2,41] The Table outlines the many areas in which PC has been shown to be an integral part of support during the pandemic.

Significant gaps in advance care planning (ACP) predated the pandemic, and many national and regional projects have long focused on prompting patients to designate medical decision makers, create advance directives (ADs), and have conversations about their wishes with loved ones and providers.[42] Yet, this concrete threat of serious illness or even death from COVID-19 has provided an opportunity to bring these conversations into the open. Patients are thinking more about how they want the contours of the end of their life to look as they see this specific threat of death by respiratory failure. Even those who have documented ADs have found the pandemic a good reason to update or change their instructions— some in the direction of more comfort-focused care but others toward more aggressive attempts at extending their life.[43−45] Provider-initiated check-ins and EOL planning conversations with patients are making providers more comfortable with these discussions, whether billed as ACP conversations under Medicare or are part of general tele-medicine visits.

Several PC teams have initiated ACP conversations proactively on admission to hospital or ICU to assure that patients receive goal-concordant care.[18,24,46] In one PC consultation study, clarification of goals in the Emergency Department by PC specialists with elderly adults who had significant comorbidities (or their surrogates) decreased the number who wished ICU-level interventions from 81%-18%.[4] ICU consultation for symptom management as well as goals-of-care and transitions-of-care conversations has increased enormously with regional surges.[3]

Although telehealth and phone ACP conversations are now recognized legally and are billable,[47] barriers to documentation of ACP wishes remain.[48,49] In New York, an executive order waved documentation requirements because of the disaster emergency, but other states have not clarified the validity of electronic signatures, "marks", or other methods of safely signing documents if in-person completion of ADs is not possible because of risk of infection, contamination, or isolation rules, either in hospital or outpatient settings.[50] Electronic registries have improved the quality, clarity, and accessibility of ADs in some states,[51] but in Colorado and many other states, they do not yet exist.

It is a fundamental responsibility for all clinicians to provide a basic level of PC even when access to specialty services may not be available, but this training is not universal or required. In Colorado, PC specialists supported other front line colleagues by developing short videos which were disseminated via the medical society, health department, and other quality-of-care organizations to help others acquire the communication and clinical skills needed to provide EOL care, particularly when this EOL and intensive symptom management may not be as much a part of their regular practice. The Colorado toolkit describes how to help patients designate an agent with medical power of attorney authorization, have COVID-19 specific serious illness conversations, and manage common EOL symptoms.[52] Toolkits were also distributed to outpatient providers and LTC institutions with model language for discussing options to care if their patients were to need to consider hospitalization. The state health department also linked to national guides and demonstration videos for primary care clinicians and staff.[20−23]

As this pandemic continues, fatigue and burnout will require increasing psychosocial, emotional, and spiritual support for staff across settings.[53] One initiative to address the stress of caring for so many critically ill and dying patients is to make toolkits such as the ones mentioned widely available to front-line providers.[2,18] Links to the national "best practices" scripts described above can be posted for staff across the wide variety of healthcare institutions. In Colorado, some institutions have initiated in-house mental health support for their staff, and the Colorado Health

Department is being developed to link frontline staff with tools and counseling services to help with moral distress.

Support of patients and families in the wide spectrum of settings is also paramount. There is growing awareness of the toll of isolation, particularly in LTC and congregate care settings, and the consequences for patients, families, and caregivers of dying alone. PC should lead the conversation around the risks and benefits of expanded visitation in multiple settings. Compassionate care visits should be considered not just for terminal EOL situations but also for the emotional care of residents who are experiencing a rapid decline in their health and well-being because of the negative effects of isolation.[25] Suffering has been compounded in settings where devices and infrastructure are unavailable to allow even virtual consultation by specialists, as well as communication of loved ones with dying family members.[54] Visitation and consultation policies need to be consistently and fairly applied, avoiding the potential for different policies across hospitals and LTC institutions. Such gaps threaten to exacerbate disparities in EOL care.

Evolving Issues

The crisis standards in Colorado for PC and hospice were approved in June 2020.[10] This pandemic, however, continues, and in addition to a duty to plan, there is a duty to learn and evolve our understanding of needs and gaps in care. Three topics have become more widely recognized in the months since our guidelines were approved in Colorado:

- Goals-of-care conversations must use the best evidence available. Mortality and morbidity statistics are changing as we learn more over time. We understand risk factors better. This evolving information should be part of discussions about the possible benefits and potential risks of critical care support, as well as survival rates.
- Excess deaths need to be better understood. Fully one-third of excess deaths since February 2020, as reported by the Centers for Disease Control, are not directly caused by COVID-19 infection.[55] Several factors may be at play, and future planning will be improved by better understanding some of these. The harms of delayed care for chronic diseases and the harms of isolation are being increasingly recognized.[56] Developing safe sites for in-person health care and good telehealth access (both internet and other devices), and on both the provider and patient end, should be priorities. Deaths due to isolation are part of this picture also, as we learn more about the morbidity and even mortality of isolation in homes and LTC facilities. As just one example, pandemic-related isolation has affected people living with dementia, significantly raising the expected number of U.S. deaths caused by dementia.[57]
- Disparities in access to support by PC and hospice workers are being highlighted and exacerbated by the pandemic. While PC specialists are available in almost all large hospitals, only 17% of rural hospitals with 50 beds or more have PC programs.[17] The percentage of Medicare decedents who receive hospice care varies widely by state, from 23%-60%.[58] Alternative care sites are often located near population centers. Access to skilled interpreters, home symptom management medications, broadband internet, and electronic devices are frequently less available in rural areas. Areas of dense living for marginalized populations, such as farm workers, prisoners, and illegal immigrant detention centers, are rarely prioritized. Addressing these disparities is critical to ensuring equitable care during the pandemic.

Conclusions

The COVID-19 pandemic has strained communities, elected leaders, patients, and clinicians. It has revealed and exacerbated gaps in care for people needing expert symptom management for acute illness, chronic and life-limiting diseases, and those near the end of their lives. Advance planning will help decrease stress on individual patients and families by helping patients, families, and their medical providers understand a patient's wishes and find ways to provide goal-concordant care. On a community level, anticipation of potential needs if crisis standards of care must be activated will decrease stress on healthcare systems by removing the burden of possible need to make allocation decisions at the bedside. Planning can also serve to improve the efficiency and flow along the care continuum, which is particularly important in times of resource scarcity and will ensure that staff, stuff, space, and support are distributed more equitably and efficiently. CSC planning must evolve as our experience with COVID-19 grows. Still, too few states have moved to create CSC recognizing the shortages beyond the ICU, leaving decisions to the local level and risking inequity and even rationing, as well as missing a chance to address suffering across the healthcare system. It is our hope that sharing the Colorado PC and hospice crisis planning measures will spur others to think and act proactively to alleviate human suffering.

Disclosure and Acknowledgment

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