

Compassion in a Crisis: The Role of Palliative Care During the COVID-19 Pandemic

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Perspective And Controversy

The disruption to health care delivery introduced by the coronavirus disease 2019 pandemic suggests a near-term future very different from a few months ago. Among the many lessons learned are the value of preparing for unpredictable medical events and the need for high-human-touch health care when serious situations arise.

In addition to logistical questions, there is a compelling existential one: “How should health care address patient and caregiver distress and uncertainty from life-threatening situations?”

We believe that the principles and practices of palliative care are one answer to this question. Palliative care is both a care philosophy and specialty clinical service that provides relief from the symptoms and stress of a serious illness with the goal of improving quality of life for both the patient and the family.[1]

The philosophy of palliative care views every human being as deserving of the best quality of life regardless of social circumstances or health condition. Thus, we use the term “palliative care” to designate the foundational and universal responsibility of all health professionals to relieve suffering through pain and symptom management, skilled communication, and support for the best possible quality of life. For patients with serious illnesses, attention by all clinicians to the experience of living with a serious illness is like oxygen: vital to thriving and stifling when absent. This is everyone’s job.

During situations of medical complexity or times of overwhelming uncertainty, clinicians consult specialty palliative care teams to provide an extra

layer of support. This phrase reflects a field-wide commitment to help as needed, when needed, in support of all. For more than a decade, inter-professional specialty palliative care teams have integrated into outpatient clinics, emergency departments, hospital floors, intensive care units, and home- and nursing home–based care delivery. Access to hospital-based consultation teams has nearly quadrupled in the last 2 decades.[2] An expanding evidence base shows that integrating specialty palliative care into usual care improves many patient, caregiver, and health system outcomes of importance. [3]

The national pandemic has highlighted the role of palliative care when stakes are high, uncertainty is rampant, and possible health outcomes are troubling. Specialty palliative care teams across the country have worked with inter-professional colleagues to develop and disseminate resources to guide goals of care discussions, processes for connecting geographically distant families and patients, tools for compassionate and truthful conversations, and safe and straightforward protocols for symptom management. [4] These efforts emphasize quickly building and scaling palliative care capacity for all clinicians.

Further, specialty palliative care teams have quickly expanded their own capacity to care for the most complex patients. For example, teams have established designated inpatient units for the critically ill, organized 24/7 hotline telephone programs for distance-based conversations with patients and worried love ones, created debriefing sessions for stressed and morally distressed health care colleagues, participated in tough system-level discussions regarding resource allocation, and integrated into emergency department and intensive care unit teams to provide just-in-time support. The demand for palliative care services from our colleagues across the continuum is unprecedented. These experiences reflect that when the going gets tough, the principles and practices of palliative care are essential and foundational to high-quality care.

The current crisis underscores two principles of palliative care which should integrate across all of health care, even outside of an active crisis. First, discussing and documenting health care preferences—commonly referred to as advance care planning—is essential for everyone, regardless

of age or health status. A global pandemic reminds us all of the fragility of human life, and the universal need for knowing one is receiving “the right care” however that is defined by the person. Recent events have increased the feasibility of advance care planning as insurers and regulators now allow clinician billing for telehealth-based delivery. Experiences to date have been positive, including high feasibility of remotely performed conversations, and strong willingness of patients and families to engage with an array of clinical team members, not just physicians.

Second, a core principle of palliative care is that of understanding the whole patient, including their life, their loved ones, and community. This involves understanding both medical and non-medical sources of strength and distress, such as social, cultural, spiritual, financial, and emotional factors. The pandemic has illuminated the importance of these domains on access to high-quality care. As the crisis waxes and wanes, disadvantaged populations lack financial and other reserves necessary to compensate for job and health insurance losses. Thus, the purposeful understanding of the person beyond the chief complaint and the problem list, coupled with questions about the role of the health care system in addressing social determinants of health, will be critical.

As the pandemic subsides, financially strapped health care organizations may be tempted to deprioritize all poorly reimbursed cognitive services, including specialty palliative care teams. But we believe the opposite should occur. The ongoing need for high-touch support for the 45 million patients with serious conditions will persist,[5] heightened by the millions who avoided medical care out of fear of entering the health care system. The rapid scaling of telehealth and other home-based care delivery techniques to care for seriously ill patients will lean heavily upon compassionate communication and distress management skills intrinsic to palliative care. Lastly, planning for the next public health crisis, akin to helping individual patients plan for changes in their own health, will require population-health level efforts to match health care resources and capacity to the needs, values, and preferences of the people they serve.[6]

The current national crisis reminds us of the individual crises faced by our patients and their loved ones, from the time of diagnosis of a serious illness onwards. And such crises indelibly alter the course of patients’ lives and relationships, threaten quality of life, introduce fear and uncertainty, and require meticulous attention to both medical and non-medical sources of distress. As we reflect on the implications of the coronavirus disease 2019 pandemic, one lesson learned is clear. In times of uncertainty and complexity, palliative care should stand shoulder-to-shoulder with patients, caregiver, clinicians, and health systems to contribute to hoping for the best, and planning for the rest.

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