Clinical and Operational Implications

Clinical Implications

Ethical and legal principles are inherent to the provision of palliative care to patients with serious illness, including principles of self-determination, beneficence, nonmaleficence, and justice. Clinicians caring for seriously ill patients understand ethical principles underlying health care delivery in the context of their own professional practice setting and discipline, as well as the laws and statues governing health care. In all contexts, the IDT provides attention to moral agency and emphasis on collaborative practice. The IDT works to recognize and be mindful of its own values and beliefs when facilitating informed decision-making, and participating in ethical dilemma resolution. As the team works to maintain relationships with the patient and family, it also recognizes the importance of maintaining professional boundaries across all settings and contexts, regardless of patient age.

Operational Implications

Clinicians caring for seriously ill patients have access to legal and ethical experts for consultation to deliver high-quality palliative care regardless of setting or location of care. Conference calls and video-conferencing provides access to experts in all care settings.

Essential Palliative Care Skills Needed by All Clinicians

Many clinicians have studied medical ethics and understand the ethical principles most applicable at the end of life. All clinicians working with seriously ill patients benefit from learning about advance care planning and common scenarios that cause ethical and legal conflicts. In addition, all clinicians know how to access legal experts, ethicists, or ethics committees, as well as specialist-level palliative care teams, to ensure the provision of high-quality care in alignment with patient goals.

Key Research Evidence

The systematic review addressed the following key question: KQ8) What is the impact of advance care planning on substituted decision-making regarding life-sustaining treatments? Thirty-six systematic reviews were identified pertaining to KQ8. The evidence table in the systematic review describes the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the *Journal of Pain and Symptom Management* (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D8-A

A long-term care setting is incorporating palliative care for patients in its day center, residential care, and long-term care programs. A physician assistant and social worker lead efforts to improve advance care planning and completion of formal directives. Varying levels of decision-making capacity pose a challenge to completing advance directives, and staff need help determining capacity. The facility develops a consultative relationship with a hospital-based palliative care team and ethics consult service for education on determination of capacity and help with challenging scenarios.
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Practice Example D8-B

A community hospice regularly cares for patients who are discharged from the tertiary hospital. A number of these patients come to hospice without clear directives, often without clear understanding of their condition, prognosis, and what to expect in the future, sometimes leading to their continued desire for attempts at cardiopulmonary resuscitation at the time of death. Hospice staff are stressed by these situations and accuse the hospital teams of failing to get these patients and families “on the hospice page.” The groups meet to identify ways they can better manage care transitions for patients and families in general, and especially for patients without a do-not-resuscitate order. The hospice liaison begins to talk daily with the palliative care team to discuss ways to meet the needs of patients. This brings valuable context and history to patients’ care plans as they transition to hospice. The hospice team has a deeper appreciation for what the palliative team has done, and what patients are able (or unable) to understand and retain despite communication, and the palliative team is better equipped to communicate to the hospice team the patient’s level of understanding and preparation for hospice care.

Practice Example D8-C

A large, multi-site health system has reviewed its patient and family satisfaction reports, as well as staff surveys, to plan new initiatives. Staff surveys reveal feelings of inadequacy in how to best care for lesbian, gay, bisexual, transgender, queer, intersex, asexual (LGBTQIA) patients and their families. In some cases, staff voice distress in providing hands-on care for these patients, particularly when they are transgender. Staff members also highlight the challenges in navigating family conflicts, such as when the biological family is in overt conflict with the LGBTQIA partners or spouses. Some family members have also reported high levels of dissatisfaction at the time of death, and instances in which patients’ wishes were disregarded, partners/spouses were not notified of a change in patient status, or were excluded from family conferences despite clear patient directives about their wishes to have their partner/spouse involved. The health system addresses this gap in patient-centered care, asking for involvement from the palliative care service and ethics committee. The Human Resources Department Cultural Diversity committee, which had previously focused only on issues of ethnicity and race, has asked a local LGBTQIA center for consultation, education, and resources to effectively address the issues identified.

Practice Example D8-D

A rural palliative care program provides care in patients’ homes across a large geographic area. The staff is often alone on these visits and sometimes do not see other team members for several days at a time. Team members express stress with some of the ethical issues they confront, particularly when patients have impaired decision-making, when they receive requests for physician aid-in-dying, and when there are family conflicts. The program develops an ethics forum for education, discussion of challenging cases, and identification of practical measures for support. The forum is hosted online, so staff can either listen in or see each other via the computer. The program provides educational podcasts for team members. Leadership facilitates dual visits of the practitioners and social workers to help with challenging cases, and facilitate greater professional and team support.

Practice Example D8-E

A hospital-based pediatric palliative care team was approached by members of the pediatric intensive care unit (PICU) care team, who expressed that they were often uncomfortable with the ethical and legal implications of withdrawal of life-sustaining therapies. The PICU care team did not feel that issues including decision-making capacity of the patient, disclosures to the child, staff moral distress, and
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Sedation of the imminently dying were consistently addressed prior to withdrawing the therapies. A multidisciplinary group, including members of the children’s hospital Ethics Committee, was convened to initiate the standardization of the withdrawal of life-sustaining therapies process that included addressing potential legal and ethical issues. The process included structured huddles, or team discussions, using a new withdrawal of life-sustaining therapies checklist to document decision-making in the medical record in real time. The checklist of items to be addressed included ensuring presence of child life, chaplaincy and social work, anticipatory symptom management strategies, confirmation with medical decision-maker and, if appropriate, the patient. Following these interventions, staff reported improvement in team communication and reduction of distress surrounding withdrawal of life-sustaining therapies.

Practice Example D8-F

A community pediatric palliative care team routinely assesses parental and child/adolescent preferences regarding goals of care, working to meet each family’s individualized communication and decision-making needs. A teen with advanced cancer disclosed to the team that he no longer wanted chemotherapy and was ready to die, but he did not want to disappoint or anger his parents. The palliative care team acknowledged the teen’s honest expression of his wishes and provided support. With his permission, the team coordinated goals of care discussions with the parents separately, and subsequently with the parents and teen together. The palliative team also drew upon the expertise of their child life specialist, the teen’s oncology team at the hospital, along with the hospital’s pediatric ethics committee to facilitate a new plan that honored all family members’ needs.