Caring for the Actively Dying

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KEYWORDS

• Communication • Death and dying • End-of-life issues • Hospice • Palliative care
• Symptom management

HOSPITAL MEDICINE CLINICS CHECKLIST

1. About 2.5 million people die each year in the United States, and most of these people die in hospitals or other care facilities.
2. The top 3 causes of death in the United States are heart disease, cancer, and chronic lung disease; most of these deaths are neither sudden nor unexpected, but the rate of hospice use in the United States remains low.
3. Despite extensive technological improvements in medical care, many patients, families, and providers remain dissatisfied with care at the end of life (EOL).
4. Hospice and palliative medicine are specialties that have evolved to address the multidimensional challenges of caring for patients with serious illness who are approaching death.
5. Palliative care may be provided as a specialist discipline, but primary palliative care and basic care of actively dying patients should be a part of all health care providers' repertoire.
6. Hospitalist physicians are well positioned to address unmet communication needs surrounding EOL care for seriously ill patients.
7. Few hospitals have well-established pathways to improve care of the dying; hospice practices may require modification in order to be translated to an acute inpatient setting.
8. Identifying patients who are actively dying can be challenging in an acute care inpatient setting.

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9. Acceptance that a patient is dying and transition to comfort-directed care should be considered for patients with advanced disease and poor functional status, especially if further attempts at disease-modifying therapy may cause more harm than good.
10. Discussions of nonmedical goals are crucial to the care of people with irreversible and progressive illness. Medical therapies are means, not ends.
11. Common symptoms that may require medical intervention in actively dying patients include pain, dyspnea, delirium, nausea and vomiting, constipation, urinary retention, and retained secretions.
12. Effective care of actively dying patients requires a team approach and the expertise of multiple disciplines, including medicine, nursing, chaplaincy, and social work.
13. Support of the family and friends, including bereavement support if possible, is an important component of EOL care.

Where do people die?

More than 2.5 million people died in the United States in 2011.[1] About 37% of those died in an acute care hospital, and another 22% died in a nursing home. About 25% died at home, and only about 14% died in a hospice facility.[2] Most deaths in developed countries are now neither sudden nor unexpected.[3] In the United States and Canada, most people die in institutions, but there has been a recent shift of death out of hospitals and into extended care facilities.[4]

Where do people want to die?

Most research suggests that people prefer to die at home.[5,6] However, preferences for site of death may change over the course of an illness.[5] Factors such as difficult-to-manage symptoms or worries about safety or becoming a burden on family members may lead people to change their minds. Preferences of where to die are also limited by choice of aggressive treatment.[7] However, regardless of where people would like to die, most do not get their wish.[5,6] There is evidence to suggest that focusing on the place of death may be less important than focusing on factors that may create a more positive experience of end-of-life (EOL) care.[8]

What is a good death?

How and where people die in the United States has changed greatly over the course of the past century. Advances in medical technology have complicated EOL decision making, but most studies examining preferred paths of dying agree on several attributes of a good death. Pain and symptom management is important, as is preservation of the dying person's dignity and clear communication surrounding medical issues.[9] The ability of people to be with family and friends, to maintain mental clarity, to have a sense of completion and worth about their lives, and to not be a burden are also cited.[10] However, studies have also found great variability in people's responses to the question of what comprises a good death.[11,12] For many, this may be peaceful and dignified, but, for some, it may be important to fight to the end even if that means experiencing what others (especially health care providers) may perceive as an awful

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