End-of-Life Care and Bereavement Issues in Human Immunodeficiency Virus–AIDS

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KEYWORDS

• End-of-life • Death • Dying • Bereavement • Aging • HIV • AIDS

KEY POINTS

- Palliative care involves the evolution of a disease long-term, such that it presents with a comingled symptom burden due to the presence of multiple medical comorbid illnesses over time.
- Associated symptoms are not alleviated by the use of disease-specific medications and tend to persist, in many ways as indicators of chronic disease.
- Hospice care is care that supports the patient when the patient is imminently facing death and dying.

This article addresses 4 areas across the spectrum of end-of-life issues and applies them to human immunodeficiency virus (HIV)/AIDS: (1) palliative care, (2) hospice care, (3) death and dying, and (4) bereavement. An issue with this spectrum from the outset is one of definition: there is a frequent lack of appreciation for the differences between palliative care and hospice care. Palliative care involves the evolution of a disease long-term, such that it presents with a comingled symptom burden due to the presence of multiple medical comorbid illnesses over time. The associated symptoms are not alleviated by the use of disease-specific medications and tend to persist, in many ways as indicators of chronic disease. Hospice care is care that supports the patient when the patient is imminently facing death and dying. These 2 areas of care overlap, but their goals are distinct. In HIV/AIDS, in which premature aging is known to occur, patients come to palliative care earlier than is expected based upon the prior history of late stage referrals. This is a result of the dramatically successful development of the antiretroviral

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(ARV) medication regimens for HIV infection. The former causes of morbidity and mortality have shifted primarily from complications due to immunosuppression to those characteristic of aging in the general population. Once hospice care in older persons infected with HIV has achieved its goals, then the care issues may move to the patient's experience of dying and, with the patient's death, on to the experience of the patient's death by others (bereavement). The hospice care stage also involves how a patient begins to mourn her or his mounting losses of functional capacities and, ultimately, to mourn her or his own passing in anticipation. Hence, each of the first 3 stages significantly overlaps, leaving the fourth stage of bereavement among the loved ones.

It has been more than 20 years since the advent of effective ARV therapy (ART), which was rapidly demonstrated to dramatically reduce AIDS-related mortality and morbidity in the United States.[1] In line with the long-term impact of those well-established treatment gains, it is anticipated that as many as 50% of persons living with HIV infection in the United States will be age 50 years or older by the year 2020. The causes of HIV-associated morbidity and mortality have melded with those of the general population, including coronary artery disease, myocardial infarction, cerebrovascular accident, neurocognitive disorder, diabetes, and cancer. Although HIV infection now may occur over an extended period of time, total physical and mental symptom burden eventually increase. Hence, the experience of HIV infection for the patient is eventually still converted to an experience in which there is a generalized expression of HIV disease progression (partly encompassed by the construct of frailty) that, to some extent, is not due to specific disorders that can be diagnosed and effectively treated. In line with these characteristics, the symptoms associated with this chronic disease burden are less likely to become the main focus of treatment attention by the primary care provider. Thus, there are several somatic symptoms associated with the longevity of HIV infection itself (or duration of HIV serostatus). These symptoms include fatigue, pain, insomnia, decreased libido and hypogonadism, deceased memory and concentration (HIV-associated neurocognitive disorder [HAND]), depression, and distorted body image. Palliative care for the chronic symptoms experienced by patients infected with HIV focuses on competent, skilled practitioners (effectiveness); confidential, nondiscriminatory, and culturally sensitive care (acceptability); collaborative and coordinated care (efficiency); flexible and responsive care (access and relevance to need); and fair access for all clients (equity). Palliative care has been associated with improved functional status in activities of daily living (ADLs), as well as with an improved quality of life for persons infected with HIV.

FATIGUE

Fatigue is among the most common and distressing symptoms associated with HIV/AIDS, affecting 20% to 60% of patients, and can be measured with the HIV-Related Fatigue Scale.[2] It is associated with increased release of proinflammatory cytokines, such as tumor necrosis factor-α, interleukin (IL)-1, and IL-6 from activated macrophages; and with clinical sickness behavior. The proinflammatory cytokines, in turn, are associated with increased HIV replication and with HIV disease progression. This cause of fatigue in HIV infection, among others, overlaps with causes of fatigue outside of HIV infection, especially in older patients. Common causes of fatigue include low testosterone levels, anemia, alcohol and substance use, insomnia, iatrogenic sources (eg, prescribed medication toxicities), obesity, diabetes, coronary artery disease, renal dysfunction, hepatic dysfunction, comorbid hepatitis C virus infection, and fevers of unknown origin. Other less common causes include cancer, chronic obstructive pulmonary disease, thyroid disease, and toxin ingestions. Of these, it is useful to note that anemia