Kindred at Home
Hospice Division

Physician to Physician:

Hospice Care and Human Immunodeficiency Virus (HIV)

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Kindred at Home - Hospice Division, a family of hospice care providers

Mention the word pandemic, and thoughts immediately focus on COVID-19. But the world experienced another type of pandemic that began as a time of fear and paranoia before becoming a true medical success story. We're talking about Human Immunodeficiency Virus (HIV) infection.

In the late 1980s and early 1990s this mystery illness initially presented with the appearance of seemingly random constellations of findings including skin and other malignancies, previously rare or never-seen infections, adult wasting syndromes, and early-onset dementia. HIV was eventually identified as the etiology; but with little understanding at first about its transmission, its discovery resulted in widespread hysteria. This led to the development and promulgation of universal body fluid precautions as HIV rose to be one of the leading causes of death across the world.

Those of us involved in hospice at that time were routinely admitting several patients a month, if not weekly. Guidelines for hospice admission were created and published. With the first glimmer of hope for this terrible disease, effective medications were developed. Over time, treatments with much better efficacy and tolerability were developed, leading to our present status such that HIV is now generally considered a chronic disease rather than a death sentence.

HIV mortality peaked in 1995 as medications started becoming available. HIV has not been among the top 15 leading causes of all US deaths since 1997. However, it remains an important cause of mortality with over 5000 deaths in 2019 and is a leading cause in some age groups: age 25-34 (10th), 35-44 (12th), and 45-54 (14th).

Today, hospice referrals for HIV have become much less common. While there are still published guidelines describing hospice eligibility for persons with HIV infection, these require greater nuance in light of today's treatments. Low CD-4 white blood cell counts and/or high blood levels of circulating HIV are indicators of serious disease. However, such findings dictate a trial of antiretroviral therapy (ART) before hospice referral, if one has not been tried. The so-called 'Lazarus Syndrome' is well documented, with individuals appearing to be at the brink of death having remarkable responses to ART, within days or weeks.

Hospice may be considered for those persons with HIV who no longer respond to ART, or who decline to take ART. More commonly, hospice cares for patients with HIV, not because of their HIV itself, but because they are dying of something else. Unfortunately, some opportunistic infections, once established, may be hard to eradicate, even with ART, resulting in progressive decline leading to death. While HIV was classically associated with certain specific malignancies, such Kaposi's sarcoma or lymphoma, it is now recognized that almost any malignancy can arise at greater frequency for those with HIV. As for all cancer patients, when oncologic treatments are no longer effective, hospice referral is indicated. Likewise, other devastating sequelae of HIV infection, such as AIDS wasting syndrome or progressive multifocal leukodystrophy (PML) also benefit from hospice care.

Because many patients with HIV who need hospice are younger than typical Medicare age groups, checking commercial insurance is necessary since many policies have different hospice guidelines than Medicare. Hospice care emphasizes comfort, ensuring advance care planning is completed, matching desired treatments to patient goals of care, and providing support for caregivers, both during the time on hospice and during the bereavement period.

While HIV infection is no longer a common diagnosis for hospice, it remains an important one. Patients with HIV, and their caregivers, can have significant symptom burden and care needs at the end of life.

Let us know how we can assist with care for your patients with HIV. We are here.

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