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Highly Active Antiretroviral Therapy (HAART) and Hospice

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There is ample information on when to initiate highly active antiretroviral therapy (HAART), but there is little guidance on counseling patients about when to discontinue HAART as the end of life nears. The decision involves a nuanced discussion of HAART's potential impact on quality of life within the context of the patient's prognosis and goals of therapy. Here are some of the HAART **benefits and burdens** near the end-of- life.

BENEFITS: **1) Prevention of a retroviral syndrome.** In one cohort study, over a third of patients who discontinued HAART experienced symptoms related to discontinuation. However, the onset of symptoms is often 1-2 months after discontinuation of HAART, and the majority of patients do not experience symptoms. **2) Treatment of syndromes** or symptoms affected by viral load or viral "fitness." The severity of HIV-related neuropathy and constitutional symptoms such as fatigue or weight loss, correlate directly to viral load & HAART may relieve or prevent. **3) Prevention of opportunistic infections.** HAART reduces the incidence of opportunistic infections that impact the quality of life of patients with AIDS. In one prospective cohort study of patients with advanced HIV disease, there was a 66% reduction in the number of new non-CMV opportunistic events with HAART. The primary mechanism is decreased viral load; however, HAART can also directly inhibit opportunistic organisms, e.g., inhibition of candidal virulence factors by protease inhibitors. Again, the potential for benefit will depend on the extent of the patient's disease and existing co-morbidities. **4) Delay the progression of AIDS Dementia Complex (ADC).** Since ADC seems to be triggered by HIV replication, HAART is a key element in slowing progression.

BURDENS: **1) Cost.** The high cost of these medications is a significant strain a hospice system's budget (typical regimen costs \$250-500/ week (www.drugstore.com). Since the role of HAART near the end of life is uncertain, hospice agencies may decide to decline payment. In some instances, patients may be admitted into hospice care for an alternate terminal diagnosis, e.g., liver failure, and remain eligible for medication coverage by their primary insurer, separate from their hospice benefit. A few patients can afford HAART meds out-of-pocket. Frequently, patients are forced to choose between hospice care and continuing HAART. **2) Side effects.** Treatment with HAART is not benign. GI intolerance, headache, and fatigue accompany most antiretrovirals. Didanosine may precipitate gout and pancreatitis; Zidovudine myopathy; Zalcitabine (ddC) peripheral neuropathy, stomatitis, and arthralgias; Efavirenz and Lamivudine depression and or anxiety. **3) Pill burden.** In a study of male veterans with a variety of chronic medical problems, perception of over-medication was associated with decreased quality of life. The decision to discontinue antiretroviral therapy for hospice patients with AIDS should be a part of comprehensive palliative care; how HAART serves the patient's overall goals for care should be the primary consideration.

Facilitating an informed discussion of benefits and burdens of HAART is an important means to help patients achieve their goals.

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