LONG-TERM CONTINUUM OF CARE FOR PEOPLE LIVING WITH HIV/AIDS

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ABSTRACT The introduction of highly active antiretroviral therapy (HAART), has created new options for those infected and affected by human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS). Most HIV-infected persons no longer die within months of diagnosis. There is now a long-term continuum of care that can end in misery or relative comfort. The introduction of palliative care in concert with curative therapies throughout the disease trajectory should be the standard of care for all persons. At the very least, the introduction of palliative care and hospice at the end of life is important to the holistic care of persons living with HIV/AIDS.

KEY WORDS HIV/AIDS, Hospice care, Palliative care.

Caregivers have devoted themselves to care for those infected and affected by human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS). As some of these providers have witnessed breath-taking changes over the last two decades in the care of those living with HIV/AIDS. The introduction of highly active antiretroviral therapy (HAART) has created new options for those infected and affected by HIV/AIDS. With these changes over the last two decades, a reconceptualization of palliative care in HIV/AIDS has occurred.

Most HIV-infected persons no longer die within months of diagnosis. There is now a long-term continuum of care instead of such draconian choices as either being treated for infection with the human immunodeficiency virus or for the sequelae of infection with cytomegalovirus, that is, with treatment that would...
inhibit either loss of life or loss of sight. The choice was for treatment of one or the other infection sequentially, but not both at the same time. This same dilemma has resurfaced for those dually infected with HIV and hepatitis C\textsuperscript{1}, although more recently some practitioners have decided to treat both diseases simultaneously. These examples illustrate options between two types of acute care.

The diagram exhibited in Fig. 1, used by Dame Cicely Saunders of St. Christopher's Hospice in London, England, depicts the relationship between acute care and palliative care. It is an inverse relationship: when there is more of one, there is less of the other. While many readers appreciate the nuances of acute care, there may be less familiarity with the concept of palliative care.

Palliative care has been defined as a “special kind of care which gives comfort, and eases pain for people who are very sick.”\textsuperscript{21} This is clearly a general definition with no specification as to what is meant by “special kind of care.” Theorists in the field offer various interpretations of this special kind of care.

Scanlon\textsuperscript{3} enhances the understanding of palliative care by stating “palliative care addresses not only the physical symptoms of the disease but the psychosocial and spiritual needs of the patient as well and extends care to the family and significant others.”\textsuperscript{3(p492)} In essence, according to Scanlon, palliative care encompasses the physical, psychosocial, and spiritual concerns of patient and family.

The definition of palliative care that is cited most often is one attributed to