ORIGINAL ARTICLE

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

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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[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."[2(p1)] 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[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."[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

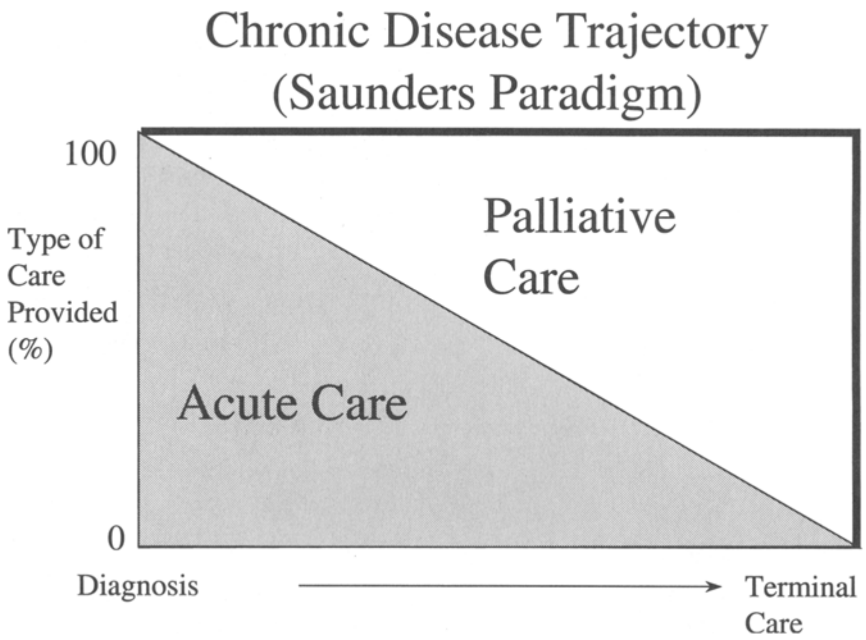

FIGURE 1 The relationship between acute and palliative care.

the World Health Organization (WHO).[4] This definition builds on the Scanlon definition:

> Palliative care is the active total care of patients whose disease is not responsive to corrective treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal . . . is achievement of the best possible quality of life for patients and their families.[4(pp11-12)]

The WHO definition is a departure, however, in that it clearly states a focus on noncurative treatment and emphasizes quality of life for patients and family. The inclusion of quality of life in HIV/AIDS care is a critical element since HIV disease and its treatment and socioeconomic aspects all affect the requirements for palliative care.

In the past, as a result of the emphasis on care that was not disease focused, palliative care was considered equivalent to end-of-life care. Contributing to this assumption, palliative care is a term that the English and Canadians have used for what is termed hospice in the US. While this perception may have been valid at one time, it is no longer accurate. Just as there are changes in what is meant by palliative care, there are also alterations in the prognostic meaning of an AIDS diagnosis. A brief review of the current understanding of HIV/AIDS provides a backdrop for further discussion about the continuum of care, including palliative care.

In the early 1980s, a diagnosis based on T-cell count and symptomatology resulted in little in the way of effective treatment. At the end of the 20th century, the range of therapeutic options was enhanced greatly by an array of medications available to treat the primary infection and a range of opportunistic infections and side effects. Given the potency of HAART, there has been a concomitant decline in opportunistic infections and in the death rate from AIDS.[5] The most dramatic change, however, has been from inpatient hospital treatment to largely outpatient clinical care.

Further, where once there was a relatively straightforward decline in health with a diagnosis of AIDS; now, there is a lengthened period of time from an initial HIV diagnosis, to an AIDS diagnosis, to death. That lengthened period of time is characterized by relative wellness. Corbin and Strauss[6] conceptualized the process of illness as a trajectory and described the phases of their illness trajectory model as comeback (from the initial illness), stable phase, unstable regular-type phase (characterized by periods of recurrence), and downward regular-type phase (characterized by deterioration and death). Different diseases are characterized by different trajectories. In addition, given the degree of pathology and other factors such as concomitant disease, individuals may remain stable, unstable, or experience a downward trajectory. Clearly, persons infected with HIV experience all of these phases, some the result of the therapeutics used to treat the disease. The difference today is that these phases are not as compressed as they once were, thus increasing the demand for palliative care.

The use of HAART therapy is not without adverse effects. Lipodystrophy, cardiac events, diabetic phenomena, and other side effects have been observed. Further, dual infection with hepatitis C results in liver impairment and an inability to metabolize antiretroviral agents. Thus, the effects of therapy alone or combined with other infections result in an illness trajectory characterized by periods of relative wellness punctuated by more or less tolerable side effects. Ultimately, many infected individuals on HAART therapy experience viral resistance and the need to change therapies. Such changes frequently are undertaken after a determination of increased viral load and the specification of resistance patterns. Due to cross resistance, therapeutic options increasingly become limited until all that remain are "salvage regimens," a term also used in oncology/hematology. Salvage regimens in effect are end-of-the-road options used to forestall further decline. The failure of salvage therapy marks the traditional period of transition from acute or chronic care to palliative and end-of-life care.

When salvage therapy fails (and note it is the therapy that fails the patient and not the patient who fails therapy), palliative care is equivalent to end-of-life care. All too often still, health care providers abandon, psychologically if not physically, those patients for whom "nothing more can be done." These individuals, consequently, may not receive appropriate care. Those familiar with hospice care know a great deal more can be done for the person for whom health-restoring therapy is not an option. Care appropriate to the person is provided by hospice.

The question may be raised as to the nature of appropriate care. The answer to this query depends on to whom the question is put. The health care provider too often concentrates on the virus and its eradication without an examination of the larger context. This magic bullet approach is admirable, but fails to consider the relevant environment, namely, the patient and his or her partner and family. The question needs to be framed differently.

What is appropriate care as determined by the patient? What is appropriate care *is* determined by the patient! It is only by understanding what is important to the patient, what his or her life goals are, that appropriate care can be postulated and confirmed. Note that appropriate care is not disease determined; it is patient determined. That is not to say that there is not a standard of care or preferred treatments for various diseases; it is to say that the art of care is fitting such care into the world view of the patient and the goals he or she wishes to achieve. Only then will the arduous regimens demanded by HAART therapy be legible to the patient. Once the regimens become the means to achieve the client's life goals, a true collaboration can develop regarding how best to maximize adherence. This is a meaningful therapeutic alliance and a key element in the adherence dynamic.[7] It is also the secret to achieving adherence to therapy. A focus on "policing" or, as health care providers say, "monitoring" compliance places providers in apposition to clients rather than in alliance. Again, the art of care is fitting such care into the world view of the patient and the goals he or she wishes to achieve. It is also a sensitivity to the readiness of the patient to embark on therapies that require behavioral change. Readiness is related to the fit with a person's life circumstances.

Thus, it is important that the health care provider be patient focused and not pill focused. The object is not to count pills; it is to help the provider understand what is important to the patient and consequently to be able to frame care in such a way that the patient perceives it as meeting personal goals. Given that adherence may involve behavior change, it is useful to consider the stages of change addressed in the transtheoretical model of change.[8,9] These stages are precontemplation, contemplation, preparation, action, maintenance, and termination. These processes of change are critical elements in patient-focused care by the health care provider. The standard of appropriate care is not only that which meets a medical or nursing standard for treatment of a disease. This is worth keeping in mind, as well, as some of the recent discussions about when to initiate palliative care are examined.

Although there is continuing debate as to when to initiate palliative care, the answer depends on how palliative care is defined. If palliative care is defined as the Canadian and English term for hospice, it implies a series of characteristics and usually a specific time frame. The time frame for hospice care of 6 months of life remaining or less was codified by the Health Resources and Services Administration regulations for hospice reimbursement. If palliative care is defined as end-of-life care, but not necessarily hospice care, then again there is a need to capture the time frame indicated by end of life. Is it when Charon awaits to ferry his guest across the river Styx? Or, is it what Ferris and Cummings[10] suggest, namely, that palliative care be initiated with the onset of disease, distress, discomfort, and dysfunction?

Ferris defines palliative care as follows:

> The combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. . . . Palliative care

> may be combined with therapies aimed at reducing or curing illness, or it may be the total focus of care.[11(p12)]

In this sense, palliative care is different from hospice care. Hospice admission includes the acknowledgement by the patient of 6 months or less to live and a foreswearing of aggressive "active" therapies aimed at cure. This bedrock of hospice care has been modified in recent years to accommodate persons living with HIV/AIDS. These individuals have made use of a variety of therapies, both active and supportive, from formal and informal providers. When these therapies are successful, hospice clients are discharged—alive.

The continuum of palliative care as formulated by the Canadian Palliative Care Association accommodates both approaches to care by incorporating comfort and supportive treatment at an earlier point in the disease trajectory.[10] In fact, as noted above, comfort care is initiated after disease, distress, discomfort, and dysfunction occur and prior to diagnosis.[10(p13)] With diagnosis, the bulk of treatment is disease specific, although comfort and supportive care are present. In other respects, their conceptualization is similar to that of Saunders, with an inverse relationship between acute and palliative care. Palliation treats the patient; acute care treats the disease. This stark distinction is inherent in a conceptualization of acute care and palliative care on opposite sides of the even less pronounced depiction of two triangles proposed by Ferris and Cummings.[10]

An umbrella of palliative care is viewed by Krammer and colleagues (12) as composed of symptom control and supportive care and hospice and bereavement care. Hospice and bereavement care are conceptualized as subsets of palliative care. Disease-modifying therapy is pictured as one small part of palliative care. Note that palliative care as portrayed by Krammer et al. protects the patient from the effects of therapy, but not from the presentation of the disease. The time frame suggested by Krammer and associates, however, is similar to that of Ferris and is initiated at the point of disease presentation or diagnosis. Although this is a major change, it is one that might have been anticipated. Earlier, WHO documents included the statement: "Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment."[4(p12)]

These sentiments are also evident in the definition of palliative care by Ferris that includes the following:

> During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practices.[11(p12)]

Further, Block and Billings[13] view palliative care as requiring a

> balancing between meeting patients' goals of optimizing quality of life while respecting patients' and families' desires to maximize length of life, rather than a sometimes single-minded pursuit of cure almost without regard to the personal costs to patient and families.[13(p764)]

These holistic definitions are congruent, also, with the focus of hospice programs in the US. What differs is the statement that "palliative care may be combined with therapies aimed at reducing or curing the illness, or it may be the total focus of care." This is truly a change in conceptual thinking from palliative care as practiced in the first quarter century of hospice care in the US and at the Palliative Care Service of the Royal Victoria Hospital in Montreal, Canada, where the focus was on palliative care alone, and palliative care was synonymous with end-of-life care. As impressive as this change in thinking is, namely, that palliative care and acute care can be provided simultaneously, much remains to be accomplished.

For many people, the focus of care during the onset of symptoms is palliative, and if the symptoms are alleviated, remains so; care is terminated with the resolution of bothersome symptoms. This gets to the heart of the matter. For the patient, the interest is always in palliation. It is a lifelong interest. Most people do not enjoy discomfort. While the focus of the physician or nurse practitioner is on the identification of the source of the problem, the patient seeks relief from distress. As a result, a dual focus is required to meet the objectives of both patient and provider. Whether palliative care is self-care or provider initiated, such care meets an important goal of the patient and must be considered in tandem with identification of the underlying problem. Such a dual focus, while present for the provider, is not always perceived by the patient, who first and foremost desires relief from the distress.

The consideration of palliative care as germane to those without a life-limiting illness creates some conceptual, if not linguistic, concerns. Many perceive acute care and hospice to be mutually exclusive. That view is held by ardent hospice proponents. Another approach is to consider cure-focused care a part of the overall palliative care focus from initial symptoms to terminal care. This is an important permutation of a focus solely on acute care throughout the illness course.

Yet another approach is to view palliative end-of-life care and hospice within a larger palliative care focus that occurs throughout the illness trajectory. In this view, end-of-life issues are identified and separated from the totality of palliative care. This view omits the larger context for care.

That context is one of health care, wellness, and prevention. It also encompasses episodes of acute and/or chronic illness and care embedded in palliative care. End-of-life care may pertain to either acute or chronic care, but both of these approaches occur in a framework of palliative care. This conceptualization has been developed from the perspective of the patient. It takes the radical stance that palliative care is lifelong (see Fig. 2).

While the focus of the provider may range from acute to chronic care and incorporate palliative care, the concern of the patient is a willingness to experience short-term pain if required for health and well-being, but with an abiding emphasis on comfort. The boundaries between different kinds of care—acute care, chronic care, and palliative care—should be viewed as permeable to emphasize the fluid aspects of this care.

The question remains as to when to cease treatment directed toward cure. This question is not the same as asking when to initiate palliative care, although these questions are often considered flip sides of the same coin. The cessation of curative treatment is a difficult question and is becoming even more of a challenge as the level of medical technology increases. The question as to when to cease curative treatment may precipitate different answers by physicians, nurses, and other providers, as well as by the patient and family. Developing consensus about treatment cessation may be easier or harder depending on the unanimity of opinion of the providers on the one hand and the level of agreement of the patient and his or her family on the other. When more and more can be done to retain life, when is that more, more than enough? The question in the era of advanced technology, however, is not only when to cease curative treat-

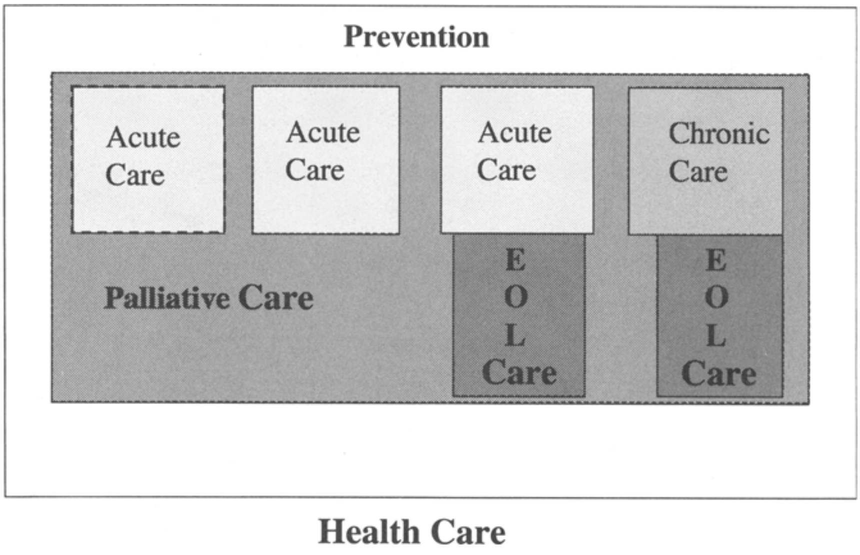

FIGURE 2 Palliative care over the life course.

ment, but also when to withdraw life-supportive treatment. There is obviously no easy answer, or this still would not be a problem for patients, families, and health care providers.

The approach of understanding the person and his or her goals and achievements, as well as his or her desires with regard to treatment, can be useful in discussing treatment decision making with patients and concerned others. The notion of a therapeutic alliance suggests a partnership by which the provider proffers the requested information and is sensitive to the need to convey information in keeping with the patient's self-determined need to know. A decision to stop curative therapy may be very difficult. It is useful to bear in mind that a reduction in one form of therapy is not cessation of all forms of therapy. It is not the absence of presence. Wherever patients are on the continuum of care, and persons living with HIV/AIDS have much improved prospects, it is a longer continuum, and that is the good news.

Perhaps the most compelling aspect in the intersection of palliative care and HIV/AIDS is the need to "support patients and promote their autonomy throughout the 'roller-coaster' continuum of HIV/AIDS."[14(p44)] Ferris and Flannery[15] address such new dimensions in HIV/AIDS palliative care as the complex dynamics of the disease process, the treatments, and the social circumstances, including stigmatization. Evolving the philosophy of palliative care for the trajectory of HIV/AIDS is often more challenging in HIV disease than in cancer. The roller coaster, or peaks and valleys, of well-being with stable health have led to a broadened range of palliative care services needed in HIV/AIDS care. Palliative care is often introduced earlier in the HIV illness trajectory and adapted to the ups and downs in health and illness that are associated with the disease.

A second challenge to palliative care identified by Ferris and Flannery[15] is the dynamic nature of HIV/AIDS treatment. With advances in treatment, persons living with HIV/AIDS are surviving longer, often with greater quality of life, but also with an increased need for palliative care services. Symptom control and psychosocial issues are greater because of the vast array of opportunistic infections and numerous organ systems affected by HIV/AIDS. Other complexities that influence the need for palliative care relate to the shifts in where and how care is provided. The increase in survival time due to advances in HIV/AIDS treatment and care has not resulted in a significantly increased average cumulative hospitalization.[16] Thus, the emphasis and requirements for palliative care are further heightened.

The socioeconomic impact of HIV/AIDS provides a compelling need for palliative care services. As Ferris and Flannery[15] describe:

> Judgements are often made about a person's lifestyle that result in physical and social isolation. Financial losses may accrue as a result of job loss and as the disease progresses, palliative care issues can be compounded by lack of housing, poor nutrition, and inability to afford treatment.[15(p10)]

Further, the roller coaster of HIV/AIDS complicates palliative care due to the unpredictability of HIV/AIDS progression, with serious illness alternating with periods of health, changes in mood, and well-being based on the unpredictability of HIV disease and chronic uncertainty about the outcome of health events and interventions.[15]

The long-term continuum of care for people living with HIV/AIDS can end in misery or in 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 as end-of-life care is important to the holistic care of persons living with HIV/AIDS. Failing this, the advances made in therapeutic options will be punctuated by misery. The challenge to palliative care in HIV/AIDS is to address the physical, psychosocial, and spiritual concerns that contribute to both the quality of life and the quality of death for patients with life-threatening diseases while focusing on the core issues—comfort and function, defined broadly and evaluated within the context of family.[17]

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