

Research Article

End Stage Care for the Person With AIDS; A Hospice Perspective

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Abstract

We are at the fourth decade of the HIV epidemic with around 34 million people worldwide infected. Although this illness today is no more considered always fatal by the most industrialized nations, due to advances in treatment, less than a third of infected worldwide have access to effective care. Despite the terminal stage of AIDS is not well defined, this paper will discuss how the hospice care provides the security of a caring environment, and provide the assurance the patients will not be abandoned. As well as we will discuss what type of care will be provided, who will provide the care, and finally, the cares and concerns about the AIDS and who is at end-stage of life.

Keywords: End-stage of AIDS; hospice care; hospice team; emotional support.

“The end of life is a dimension that can never be known until we experience it ourselves. To live life until the very end in comfort and with the right support illustrates the quality of the society in which we live.” [1]

Introduction

The greatest fear of those who are the terminally stage of AIDS is of being left alone and dying without anyone by their side, and not death and pain. Hospice provides the emotional support for patients and the families with the assurance that they will not be abandoned as well as helps alleviate some of problems of terminally ill patients. The emphasis of the emotional support is on making the process of dying a coming-together experience for the patient and family [1]. In addition, hospice can contribute a frank and open discussion about the value of treatment near the end of life [2]. The focus of the hospice approach and philosophy is to help the dying to live as fully as possible during the time that remains, which is possible through the control of symptoms because the hospice care seeks to eliminate the suffering that accompanies the dying process [3].

Nowadays, we are at the fourth decade of the HIV epidemic. Although this illness in the past was considered nearly always fatal, today, due to advances in treatment, it is viewed as a chronic disease under relatively safe and predictable control, in most industrialized nations. The introduction of effective antiretroviral therapy (ART) in the mid-1990s, especially by the industrialization nations, resulted at the dramatic drop in the death rates from HIV and in an increased longevity of the AIDS patient. As the patients are living longer and more the number of new infections, despite the number of new infections fell off sharply as well, the average age of the HIV-positive population is rising. At the year 2015, according the CDC, almost 50% of the HIV-infected patients in the USA would be over 50 years old. The risk of transmission will also rise as the number of patients in this age group rises, not only due to increased risky sexual behavior but also as a result of higher prevalence rates. Around 34 million people worldwide are infected with HIV and less than a third of those infected have access to effective care. The epidemic is still raging in many parts of the world, particularly in countries with minimal healthcare infrastructure for example, some African nations there are areas where the prevalence rates of HIV exceed 30% in the adult

population [4].

The terminal stage of AIDS is not well defined. Although many die during a first acute hospitalization for pneumocystis carinii pneumonia, the final phase of irreversible decline is marked by uncontrollable and successive opportunistic infections with progressive general deterioration and debilitation, and often deteriorating mental capacity [1]. Usually, the patients qualify for hospice when they have a prognosis of survival of 6 months or less and are willing to give up the curative treatments [5].

In this paper, based on our experiences and knowledges as well as of other researchers, we will discuss issues that comfort people with AIDS in the end-stage disease. We will address where these patients will receive care, what type of care will be provided and who will provide care. Because the health care workers' attitudes and ideas about persons with AIDS (PWAs) are very relevant, especially if they resist the hospice's concept. Finally, we will talk about the role of both hospice care and aggressive care in the hospice program and the cares and concerns about the AIDS and who is at end-stage of life.

The Hospice Care

Hospice is primarily a philosophy of care and a program for the terminally ill, not necessarily a facility. The program can be carried out in the patient's home, or in a department of a acute-care hospital, or in a separate facility attached either organizationally or physically to a general hospital [6]. The interdisciplinary care (medicine, nursing, chaplaincy, social work, and other specialties when appropriate), which is provided by the hospice, focuses on improving quality of life for persons of any age who are living with any serious illness and for their families [5].

The hospice care provides the security of a caring environment, and provide the assurance the patients will not be abandoned. The

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hospice focuses on patient's quality of life, emotional and spiritual well-being, symptom burden, care giver burden, and bereavement [2]. Key components of hospice care include identification and support of spiritual distress, assessment and treatment of physical and psychological symptoms, specialized communication to establish care goals of care and assistance to support the complex medical decision making, and coordination of care [5].

The aging of people with AIDS requires a focus on mental health, chronic pain management, and polypharmacy, as well as mechanisms to address social needs, which includes the stigmatization and isolation, housing stability, and economic hardship. These challenges contrast with those faced from the typical hospice care population, typically older than 80 years with physical and cognitive disability resulting from senescence and dementia. Because of diversity of the population of patients with AIDS, the needs may differ from the priorities of their health care providers [7].

The goals of hospices are to provide relief from the distressing symptoms of the disease and provide sustained expert care because the major ingredient of end stage care of person with AIDS is the symptom control. The common symptoms in the late-stage of AIDS could be weight loss/anorexia, fever/sweats, fatigue/weakness, nausea/vomiting, constipation, diarrhea, dyspnea, cough, increased secretions, pruritus, and dry skin. After physicians and nurses determine the cause of the symptoms, attempts are made to apply treatment that will alleviate them and avoid unnecessary side effects. All the efforts must be to prevent symptoms by applying appropriate therapies at intervals that maintain a continuing beneficial effect. The continuous monitoring of the symptoms allows that the hospice's team proposes the immediate modification of care by responding to changes in the patient's condition [6].

At last, the hospice approach centers not only on helping who is in the terminal stage of AIDS to maintain the dignity and humanness of the dying process and providing sophisticated medical and nursing care, but also their loved ones with the emotional support [1].

The Hospice Team

The care is provided by an expert team whose members include the physician, nurses, social workers, the family, and trained volunteers. All clinicians who care for people with serious illness must be competent in generalist palliative care skills, including interprofessional collaboration, communication, and symptom management [8] because the patient's entire spectrum of needs must be addressed (intellectual, physical, emotional, financial, social, and spiritual). For a hospice program to be effective, each team hospice's member will have the opportunity to learn from the other members, each of whom brings special perspectives to the program [1].

Most physicians and other health care professionals currently in practice have had limited or no formal training in these areas despite this philosophy of hospice care now a rapidly growing medical specialty. Evidences show that palliative care teams not only enhance the quality of health care for persons living with serious illness and for their families but also reducing medical expenditures [5]. However, according Kendal et al [7], the costs of care in the last year of life for person with AIDS is almost 50% greater, or more than \$27,000 more per person, than those without AIDS.

Physicians

The physicians play a crucial role in the hospice program because they have the responsibility and professional and legal authority when they certify legal death and secure reimbursement for ancillary health care services. Additionally, they establish a valid diagnostic, prescribe medications that provide the most effective palliative care, and guide program administration so that hospices meet the needs of their

patients and the families [9].

However, some physicians are resistant to the concept of hospice. The first reason underlying this resistance is the physicians' own attitude toward death because they are strangers to the real issues of dying. Historically, the physicians have been taught to diagnose, treat, and cure, and not to deal with the death, especially nowadays that medical science has learned to heal much more effectively. In addition of their arsenal of antibiotics and other interventions, most physicians believe they can cure most diseases. Thus, death has come to be seen as unnatural and as the enemy of the physician [10] as they look at death as failure and therefore shy away from those dying patients whom they believe they have "failed" [11]. A study comparing physicians' fears of death with the fears of patients revealed that physicians showed significantly more fear of death than either the healthy or sick lay people, included some terminally ill patients [1]. While this fear seems today to be a factor of physicians' selection for the medicine as a career, it also may prevent them from being able to help patients deal with impending death [12].

Another reason for some physicians' resistance to hospice is that they see it as a system of giving care rather than prescribing cure or as a nursing function. When diagnosis, prolongation of life, and cure do not seem more relevant, physicians frequently conclude that they have nothing to offer and consequently they tend to remove themselves from the picture. However, even the cure is no longer a possibility, a great deal remains for physicians to do for the dying person [10]. They can help the patient cope with the frightening experience of the dying process as well as the indignity of bodily degeneration, which includes offensive odors, loss of bowel control, disfiguring lesions, dependence on others, suffocation, pain, abandonment and dementia. Caring physicians can not only explain the course of the illness clearly to patients and anticipate problems to allow for early intervention but also they can assist patients in gaining some measure of control over their lives by teaching them the proper use of medications and other ways to remain responsible of their health [13].

Nurses

Care of the person with AIDS at the end-stage of life requires the more skilled application of nursing knowledge. The nurses assess the patient's physical conditions, provides interventions, discusses with the physician relevant changes in the patient, as well as they teach the team members about infection control, pain and symptom management, in most hospices programs.

What the nurse offers depends largely on the patient's condition, the degree of independence, and the symptoms present in the illness. The care goes beyond symptom and pain control, and involve items as bathing, control of odor, mouth care, care of hair, as well as bowel and bladder care [1]. In the case of a person with AIDS, because the course of this disease is so unpredictable, a nurse must be on call twenty-four hours per day [14]. Finally, the nurse may take direct charge of some of these services, or depending on the setting, they may be provided by attendants or volunteers [1].

Volunteers

Volunteers are important members of the hospice team and, in large part, contribute to making the hospice a caring community. They may serve in a variety of positions: direct care givers, receptionists, writers, public speakers, photographers or researchers. By playing a large role in bringing about the high level of personal care found in hospices, they must be carefully interviewed, screened and trained before being placed on a hospice team. A good volunteer knows the patient and family and becomes a friend, which can be one of the most important functions the person could perform [1].

During the end-stage of AIDS some requirements are critical

for the hospice team such as the worker's availability, reliability, empathy, and ability to respond emotionally to the client. Although, some countertransference issues are common associated with the care of the person with AIDS, which include fear of contagion, fear of the unknown, fear of dying and death, homophobia, denial or helplessness, over-identification, anger, and the need to profess omniscience.

The staff can become emotionally overwhelmed with little time to process and reintegrate when the client is near of the death or because of the increasing number of AIDS patients. In this case, five recommendations will help palliative care providers cope more effectively with the problems associated with caring for AIDS patients, according Buckingham [1]:

- 1-Clarify for AIDS patients and their loved ones what hospice cannot do for them before specifying what it can do.
- 2-Keep your professional footing. Because hospice personnel are usually close in age to AIDS patients and their loved ones, it is easy to overidentify and thus to become enmeshed in patients' struggles to live and die with AIDS.
- 3-Learn to listen to your own feeling of helplessness and frustrating.
- 4-Speak the unspeakable in order to disengage various conflicting values and emotions in the patient-family unit.
- 5-Get in touch with your own fears about AIDS – fears of contagion, death at a young, homosexuality, and the drug culture.

Hospice care versus aggressive care for the person with AIDS

The person with AIDS usually pursues palliative therapy while simultaneously pursuing curative therapy, but the discussion among patients, physicians, nurses, and other team member is vital to decide when to stop the curative therapy. Even in the terminal phases, the curative therapy may be appropriate in some cases and may extend a patient's life, but the patient will have to make the decision whether the extra time gained justifies the steps of the treatment to extend the life [15]. Nowadays, physicians are referring PWAs (persons with AIDS) to hospice programs with more frequency. While this is often an appropriate action, there is a potential danger that the physicians' frustration with being unable to cure these patients may lead them to relinquish treatment and to make the referral too soon [10], particularly with the hope for a cure ever present. The onset of dementia, successive or multiple opportunistic infections, or irreversible debilitation may signal the need to consider a shift in the focus of treatment from aggressive care to a hospice approach, which is designed to allow the patient to die in dignity and comfort [1].

The final decision about the curative therapy may be chosen by the patient with the support of all team members, who should provide their honest input [16] The patient must be considered the key member of the team, deciding home or hospital management, preferences for treatment, type and number of social interactions, and the rules of confidentiality, which is when the patient determines what information is shared with nonmedical members of the team [1].

However, the decision about the issue to refer the patient to a life-support system is particularly difficult when the person with AIDS is no longer competent because of a neuropsychological condition. Who will make this decision if the patient is not more capable of participating of this discussion? In the most cases this decision to put the patient on a life-support system is taken by the family, who is considered part of the unit of care. But who should be considered "family"? All these factors make discussion about the future course of treatment problematic [17].

Unfortunately, the right time to reach this decision to refer the patient to a life-support system is early on the course of the disease, when the patient is capable of participating. Although the "living will" should be considered, this is not done in many cases because the health care providers are reluctant to discuss this issue with new patients when they are still well. The problem is aggravated when the patient is young, especially young women and children, or if the patient is what some caregivers consider "sympathetic" victims such as blood transfusion-related cases, and babies [1].

Cares and Concerns

Those who works for people with AIDS must be aware that the patients oftentimes carry emotional "baggage" (such as anxiety, fear, isolation, rejection, depression, hostility, anger, and denial) in order to be effective in administering care. The patients' anxiety may be partially related with the absence of specific diagnosis or may also be related to the patient's self-image, because AIDS can alter one's self-concept. Therefore, the causes of distress and anxiety for the patient and the family are always of concern to the hospice staff [18]. As the nurse is a very important person in the life of the person with AIDS, she or he should provide an atmosphere of individual acceptance of the patient. This means that the nurse must put aside one's personal prejudices or feelings about the patient's lifestyle and background. Due to the nurse's intimate contact with the patient, the patient quickly finds out if the nurse is bringing a personal agenda. At last, the nurse should provide the opportunities for the patient express the strong feelings being experienced during this crucial time [1].

A person with AIDS usually dies much earlier than their non-HIV counterparts and oftentimes more marginalized because of lower income [7]. Some hospice programs adopt the traditional criteria for admission of life expectancy, palliative care, and a primary support system, they struggle to admit and care for people with AIDS. By hearing and experiencing these limitations on admission, people with AIDS often resist being hospitalized and served by hospice programs [1]. In this way, most Canadians with AIDs prefer to die at home, despite they were less likely to receive palliative home visits near the end of life, according Kendal et al [7]. This preference highlights that the hospice programs need to understand, develop, and implement patient centered care settings that address the complex needs of HIV population.

Conclusion

While providing adequate care for the terminally ill is challenging, the comprehensive approach to hospice care at home is increasingly recognized as a model for treatment of patients entering the progressive, chronic or terminal stages of AIDS. Multiple opportunistic complications and central nervous system impairment may cause AIDS patients additional time to be supervise before death. Although the goal of hospice care for people with AIDS is to assist the patient and family to obtain comfort and achieve optimal function, this becomes a special challenge given the severity and unpredictability and of the AIDS.

The emphasis of the emotional support is crucial to make the process of dying a coming-together experience for the patient and family. Even after death has occurred, emotional support for the surviving family members continues, which may include individual bereavement support, bereavement groups, and follow-up visits by hospice staff. Even though dying is part of the process of living, the issue of death has been hidden, denied, and thus feared by our society. The attempts by a few lay people have brought the important issue of death into people's consciousness, but more efforts are needed to educate the public and medical community about the importance of hospice care and its philosophy of allowing AIDS patients to live with dignity, their last stages of life.

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