

End-of-life issues in AIDS: the research perspective

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In 1999 alone, HIV/AIDS-associated illnesses caused the deaths of about 2.8 million people worldwide, including an estimated 480 000 younger than 15 years¹. Some 13.2 million children have lost their mothers or both parents since the epidemic began¹. In this paper we describe research initiatives being pursued at the National Institute of Nursing Research, but first we examine existing publications to provide some background information.

END-OF-LIFE CARE FOR AIDS IN THE USA

In the USA, AIDS-related deaths have been declining since 1996². While these trends are encouraging, they lead to a false impression that, once people have access to advanced antiretroviral therapies, end-of-life issues cease to be of great concern. This is not so. Moreover, large disparities in AIDS deaths between different ethnic groups³ (Figure 1), coupled with knowledge of the importance of cultural competence in approaches to ethnic minority groups, indicate that interventions should be targeted more to the demographics of the epidemic. The most common approach to end-of-life care in the AIDS population has been to apply the interventions (hospice, palliative care) used in cancer patients. We lack information on the best ways to provide care in the unique circumstances of the AIDS epidemic.

The hospice philosophy rests on the assumption that dying is not only a natural part of life but also an event that can and should be as meaningful as life's other important events. Thus, hospice focuses on assisting patients in having a peaceful death, in which they are free of pain, are aware of what is happening to them and around them, and have as much control of unfolding events as they want.

With AIDS and many other life-threatening illnesses, medical breakthroughs are expanding the timeframe for palliative care and blurring the definition of end of life. The availability of advanced diagnostic techniques and treatments can sway the care of terminally ill AIDS patients in the direction of curative care, so the end-of-life experience is determined by the available technologies. Palliative care in the United States has yet to achieve wide acceptance within the American medical community, where treatment success is customarily measured in terms of lives saved or, in effect,

deaths postponed. An approach that eases a patient's path towards an imminent death faces great difficulty in being recognized as legitimate, much less honourable. This limited view of palliative care stems partly from its 'low-tech' nature. Many people mistakenly believe that palliative care comes into play only after medicine has exhausted all the skills and technologies that might bring about a cure. Palliative care and medical research and technology are not mutually exclusive. Far from turning its back on the latest findings and state-of-the-art technology, good-quality palliative care draws on them in the determined pursuit of its own goal—a peaceful death. Yet, under certain circumstances, patients may receive radiotherapy, chemotherapy and surgery as part of their palliative care⁴.

Delivery of palliative care

The history and current drawbacks of hospice care in the USA have been reviewed by Cassel and Demel (p.433). Coverage under the Medicare hospice benefit includes visits by the hospice team, durable medical equipment, and supplies. Medicare also provides coverage for bereavement counselling for the family and caregivers for up to one year after death of the patient. Medicaid, the federal programme of health coverage for indigent Americans, includes a similar benefit for hospice services.

Data on the use of the Medicare and Medicaid hospice benefits by persons with AIDS are difficult to find. The AIDS diagnosis was not mentioned in a study of Medicare beneficiaries' costs and use of care in the last year of life⁵.

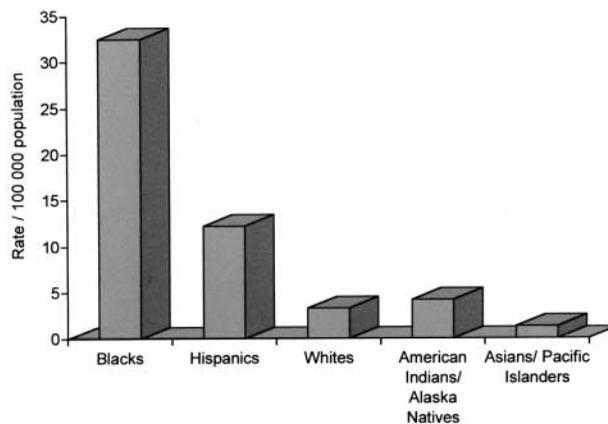


Figure 1 AIDS-related deaths in the USA in 1998 according to ethnic background (from Ref. 3)

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Table 1 Barriers and facilitators to communication (from Ref. 8)

Barriers		Facilitators	
Patients	Clinicians	Patients	Clinicians
Not wanting to talk about getting sick	Perception patient was not ready to talk about end-of-life care	Trust in care provider	Good relationship with the patient
Wanting to focus on staying alive	Patient had not been very sick yet	Perceptions of clinician caring	Trust
Equating end-of-life decision-making with assisted suicide	Patients' end-of-life preferences would change over time	Perceptions of clinician competence in AIDS care	Expertise
Providers not feeling patients were sick enough to have end-of-life discussions	End-of-life discussions would take away hope		

One of the authors of that study suggests that the AIDS diagnosis is invisible in the database because deaths are usually coded according to immediate cause, such as pneumonia or malignant disease (Lunney J, personal communication).

For a patient to become eligible for Medicare coverage of hospice services, a physician must certify that the person is terminally ill and can be expected to live only for another six months or less. Obviously, this determination is not always easy to make with accuracy, and Congress has amended the original Medicare benefit to allow for extensions.

Many people who are eligible for Medicare and Medicaid hospice benefits still do not receive them or receive them only a few days before death. The usual explanation is that physicians tend to be overly optimistic about their patients' prognoses or are reluctant to dash their patients' hopes by delivering the six-months-or-less prognosis necessary for benefit eligibility. Of particular relevance to the delivery of palliative care to patients with AIDS is a series of studies showing that Hispanics and African Americans do not enter hospice programmes in significant numbers in the United States. In a study in New York, African Americans expressed a reluctance to sign advance directives and do-not-resuscitate (DNR) orders for fear that their care would be abandoned⁶.

The reluctance of patients to sign advance directives or agree to DNR orders may be due in part to the difficult nature of end-of-life conversations. In a study conducted in the north-west United States, persons with AIDS from non-white ethnic groups were less likely than non-Hispanic whites to report that they communicated with their primary care provider about end-of-life preferences⁷. People with low incomes, injection drug users and women with high-risk sex partners tended to report poor communication. In contrast, patients who had completed a living will or durable power of attorney for healthcare reported a better quality of communication. Satisfaction with

care was strongly associated with quality of communication. The authors recommend that, since socioeconomic status and ethnicity are associated with both the occurrence and the quality of end-of-life communication, future interventions to improve communications about end-of-life care should consider the effect of these variables.

In a follow-up analysis, the same group assessed the reasons why patients and physicians do not talk about end-of-life care (Table 1)⁸. Non-white patients, injection drug users and women were more likely to feel that talking about death would bring it closer. The barriers and facilitators to end-of-life communication between persons with AIDS and their care-providers suggest that effective palliative care will demand end-of-life communications that focus on the needs of individuals as well as specific groups.

PALLIATIVE CARE FOR AIDS IN THE UK

In the UK, Guthrie and colleagues evaluated whether or not people with HIV in London were able to die where they wanted⁹. The investigators posited that, for patients, dying where they planned implies that they are aware of their prognosis, that their symptoms are controlled, and that they are involved in decision-making during the late stages of the disease. Information was extracted from existing databases at St Stephen's Clinic in Central London for the years 1982–1993. Early in the epidemic almost all people with HIV died in the hospital, but in the late 1980s there was an increase in deaths at home and in hospices. By the end of the study period, almost 60% of people were dying where they had planned—but many still chose to die in the

Box 1 Domains of high-quality end-of-life care (from Ref. 10)

Adequate pain and symptom management
Avoiding inappropriate prolongation of dying
Achieving a sense of control
Relieving burden
Strengthening relationships with loved ones

hospital. Guthrie *et al.* conclude that hospitals must continue to provide for the needs of patients dying with HIV/AIDS.

Just what the needs of dying patients are was evaluated in a qualitative study of patients' perspectives of the elements that comprise good end-of-life care¹⁰. Three patient groups—dialysis patients, people with HIV infection and residents of long-term care facilities—identified domains that define high-quality end-of-life care (Box 1). These domains were similar to models derived from experts such as the American Geriatrics Society and the Institute of Medicine of the National Academy of Sciences in the US; however, the investigators highlight important differences between the patient-derived and the expert-derived domains. The patient-derived domains were simpler, more specific, not bound by established concepts such as 'global quality of life' and focused on outcomes.

Investigators in the UK also retrospectively examined the experience of a generic hospice providing care to patients with advanced HIV disease¹¹. Only 26 patients were admitted during a 4-year period (0.85% of new admissions), supporting Guthrie's conclusion that hospitals will continue to be a major site of palliative care delivery. Referrals to hospice were primarily from hospitals (70%) rather than practitioners. The median length of stay for all patients referred to hospice was only 19 days—suggesting that, as in the US, referrals to hospice come late in the illness trajectory. Some of the symptoms experienced by the patients, such as weakness, immobility, and weight loss, were not amenable to interventions; others, such as pain, dyspnoea, and confusion, were. Services provided to patients reflected the expertise of the full multidisciplinary team. The authors conclude that generic hospices can offer important services to HIV patients who are at the end of life and that professionals need to consider referring these patients to such hospices.

In a prospective study by the Regional Infectious Disease Unit in Scotland, health service and hospice use by HIV-infected individuals was evaluated for 1992–93¹². Most of the 513 patients (72%) had been infected through injection drug use. As expected, patients with lower CD4 counts had more and longer hospitalizations. Resource use in this Scottish centre was remarkably similar to that in other British centres, despite the differences in patient populations (risk groups); population variation was less important in determining resource use than was clinical or immunological stage. Hospice use was twice as high among people who were relatively well (pre-AIDS and CD4 count $\geq 200/\mu\text{L}$)—a finding attributed by the authors to increased respite care, the effect of risk group (injection drug users) and socioeconomic status. Seemingly, hospice care can be useful early in the AIDS illness trajectory.

In summary, the research base is limited but we can identify some areas upon which to build future research. At

present, good-quality end-of-life care can be defined by five domains identified by patients (see Box 1). The site of delivery of palliative/hospice care (home versus hospital) may be less important than implementation of the philosophy. Generic hospices, which have in the past concentrated on oncology patients, may improve outcomes for individuals dying with AIDS. In addition, hospice care should perhaps not be confined to the time identified as the end of life but should encompass a longer trajectory.

INITIATIVES SPONSORED BY THE NATIONAL INSTITUTE OF NURSING RESEARCH

The 1997 report from the Institute of Medicine noted significant gaps in scientific knowledge about end-of-life care and stressed that these gaps 'require serious attention from biomedical, social science, and health services researchers'¹³. In this same year, the National Institute of Nursing Research (NINR) co-sponsored, with other Institutes at the National Institutes of Health (NIH), a research workshop on 'symptoms in terminal illness.' Afterwards, NINR published a programme announcement, *Management of Symptoms at the End of Life*, and a request for applications, *Research on Care at End of Life*, to stimulate research on these issues. The large number of applications for funding led to NINR's designation as the lead institute at the NIH in the drive to promote the science of end-of-life care. Building on these earlier initiatives, a programme announcement, *Quality of Life for Individuals at the End of Life*, was published by NINR and six other Institutes in August 2000. Applications were invited for studies on end-of-life management of physical and psychological symptoms, communication between patients and providers or patients and families, ethics and clinical decision-making, and caregiver support. The programme announcement specified an interest in research on patients' end-of-life issues across the lifespan, including neonates in intensive-care units, children with AIDS, teenagers with cancer, and young adults with degenerative diseases.

Of some twenty-two research studies and seven training and career development awards now being funded, only a few focus on end-of-life issues in HIV/AIDS. To date we have received few applications on this topic. One study that we co-fund with the National Institute of Mental Health investigates the desire for death among terminally ill patients with AIDS. Another is looking at advance directives in patients with AIDS. We plan to continue building this area of science so that we can provide the best care for patients with HIV/AIDS as well as the data that policy organizations need to make informed decisions.

NINR is pursuing other aspects of end-of-life care and is a major sponsor of a new study by the Institute of Medicine

on paediatric end-of-life issues. In addition, an NIH-wide research interest group on end-of-life issues was organized by NINR in October 2000, and one of its first actions was to host an open forum in which the NIH community and the general public could consider future directions for end-of-life research. Four end-of-life experts made presentations on technologies used at the end of life, cultural and ethnic dimensions, palliative care, and ethical issues. The forum was timed to build on momentum generated by a highly publicized documentary series, *On Our Own Terms—Moyers on Dying*, that was broadcast on public television across the US in September 2000.

CONCLUSION

For science to inform policy we need to acknowledge the impact of the demographics of the AIDS epidemic on the delivery of end-of-life care and construct intervention studies that are targeted to those individuals. The AIDS illness trajectory needs better explanation so that the definition used to determine hospice payment is not based on arbitrary time-frames, and so that effective palliative care interventions can be applied early in the disease process. We also need to find ways to change the perception held by many healthcare providers that palliative care is less interesting and less challenging than high-technology interventions. By investigating the domains of high-quality end-of-life care we can determine the best approaches to caring for persons with AIDS who are at the end of their lives. Finally, we need to tailor measurement instruments for disparate cultures and agree on intra-national and cross-national measures needed to evaluate end-of-life care. Joined by its NIH partners, NINR is positioned to continue developing these research

initiatives to keep pace with emerging understanding of research needs in the area of end-of-life care.

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