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DELIVERY OF NURSING CARE

To date, most non-volunteer health care delivered to persons with acquired immunodeficiency syndrome (AIDS) has been in acute care hospital settings, even though the course of the disease is such that people often have months of relative wellness between episodes requiring hospitalization. AIDS and associated conditions will place an enormous burden on the health care delivery system because of increased patient load and increased aggregate costs of care. The United States Public Health Service (USPHS) estimates that the direct health care costs for persons with AIDS will be between \$8 and 16 billion in 1991, which represents 1.2 to 2.4 percent of the expected total national personal health care expenditures (Coolfont, 1986). Scitovsky and Rice (1987) estimated that the average lifetime costs of treating a person with AIDS in 1984 dollars ranged from \$60,000 to \$75,000, Hellinger (1988) estimated treatment costs in 1988 to be about \$57,000 (in 1985 dollars) rising to about \$61,000 in 1991, mainly because of the cost of azidothymidine (AZT). By 1991, it has been estimated that 12,831 US hospital beds will be occupied by AIDS patients, outnumbering the beds occupied by patients with lung cancer or automobile accident victims (Sundwall & Bailey, 1988).

Both the USPHS, through the Health Resources and Services Administration, and The Robert Wood Johnson Foundation awarded demonstration grants to communities in 1986 to develop integrated networks of services for prevention, treatment, and support of persons infected with the human immunodeficiency virus (HIV) (Report of the President's Commission, 1988; Sundwall & Bailey, 1988). One of the stated goals of these service demonstration projects was to "identify unmet service needs and take steps to meet those needs" (Sundwall & Bailey, 1988).

State of the Science

Communities have taken different approaches to providing care to HIV-infected individuals, but little formal research has been conducted on systems or models of care. The literature consists primarily of reports from single institutions, and recommendations for what should be done. A model developed in San Francisco incorporates a spectrum of coordinated services ranging from residential to acute care, providing for continuity outside the hospital setting. Many other communities have relied heavily on acute care hospitals for all care because they lack alternative facilities.

Care Across the Spectrum of Illness

There has been some consensus that coordination of a spectrum or continuum of services is needed (Coolfont, 1986; Hardy, 1986; Institute of Medicine (IOM) 1988; Report of the President's Commission, 1988; Sundwall & Bailey, 1988). For example, patients need an array of services that range from acute care to outpatient care, home care, long-term care, hospice, and

others. Services should include counseling for the patient, family, and significant others, financial and legal advice, education about AIDS and its prevention, and bereavement support and other psychological counseling. The needs of individuals for health care services will also vary depending on the duration of their infection with HIV and the type and severity of their symptoms. Many people who may have been exposed to HIV need access to testing and counseling facilities. Once determined to be anti-body positive, infected individuals need regular follow-up and assessment, education and counseling, access to treatment if symptoms develop, and supportive services. Symptomatic HIV-infected persons need different types of services in different settings at various times; for example, there may be an acute episode of *Pneumocystis carinii* pneumonia requiring hospitalization, followed by several months of relative wellness requiring outpatient follow-up. Some, especially those with HIV-related dementia or other chronically disabling conditions, need long-term care either in the home or in an inpatient facility. The need for supportive services also varies depending on symptomatology, premorbid health, and available social support. To date, the financing of care or services for those without private insurance who are HIV infected but not diagnosed with AIDS has been problematic. In many states, such persons do not qualify for Medicaid or other forms of public assistance, but may not be able to afford personal health care expenses. Without adequate means of paying for care, access to needed services is restricted.

The Coolfont Report (1986) recommended that all sectors of the health-care delivery system work together to determine appropriate care needs at different stages of the disease, costs of care, and cost effective methods to provide needed services. The IOM (1988) identified the need to document and evaluate the various types of services across settings, such as hospitals, terminal-care facilities, and home services that are now available to HIV-infected persons in certain communities. The report also emphasized the importance of understanding the dynamics of family involvement in health-care services and the responses of families in different social, economic, and religious contexts.

The Health Resources and Services Administration, and The Robert Wood Johnson Foundation have supported evaluation research as part of the service demonstration project program. The National Center for Health Services Research and Health Care Technology Assessment (NCHSR, [now the Agency for Health Care Policy and Research]), in a Program Note of October 1988, declared their interest in sponsoring HIV health services research on cost and financing of care, health status measures and information systems, access/barriers to care, quality of care, health systems analysis, cost effectiveness of alternative service and organizational strategies, and provider issues.

A promising strategy for providing continuity of care is case management. The Child Services Division of the Health Department in New Jersey provides case management services, home care, financial counseling, equipment, and transportation (Klug, 1986). Case management, with nurses as case managers, may offer an efficient and cost-effective model for providing continuity of care (Clausen, 1984; Morrison, 1989), but warrants careful evaluation research. Insurers may pay for the most cost effective method of care, even if the service is not usually covered; e.g., home instead of inpatient care (Baer, Hall, Holm & Lewitter-Koehler, 1987; O'Brien, 1987; Valdiserri, 1988; Young, 1988). A transagency approach has also been used (Woodruff & Sterzin, 1988). Usually no organized plan for continuity of care is provided. Other models of providing continuity include a "Disposition Worker" who arranges for follow-up care after discharge from a medical or psychiatric unit (Baer et al., 1987), and an outpatient-based continuum model (Jackson, Healy, Straube, McPherson, & Greenwalt, 1986). The costs and outcomes of various models and the most effective role for nursing deserve study.

Models of Inpatient Care

In hospitals, the care of HIV-infected individuals has been organized primarily in two ways, centralized or dispersed. In the centralized method, the care unit or AIDS ward (with overflow dispersed throughout the hospital) is identifiable as a separate entity in the hospital. The staff may be volunteer only, as at San Francisco General Hospital where the patients reported very compassionate care (Jenna & Mount, 1988). At St. Clare's in New York, a mixed volunteer and assigned staff is used (Jenna & Mount, 1988; McGuirk & Miles, 1987, Burda & Powills, 1986).

Such a specialized unit structure has placed value on the availability of a knowledgeable and willing staff to participate in program planning. Carefully planned comprehensive orientation and in-service education programs must be provided for staff undertaking this new assignment. The importance of having unit managers, supervisors, or head nurses who are informed and concerned about the treatment needs of persons with HIV infection has been emphasized (Morrison, 1987).

Five theoretical advantages to the centralized approach have been cited by its advocates: reduced length of hospital stay through early discharge planning, financial need planning, and cost containment (DeHovitz & Pellegrino, 1987); increased sense of community and social support from peers (DeHovitz, 1986); decreased concern by the public and other patients (DeHovitz, 1986); comprehensively meeting medical and psychological needs of patients by a dedicated staff (DeHovitz, 1986); and consolidation of institutional resources (Morrison, 1987). Well planned, organized, and coordinated programs may cost less to operate. Cost can further be contained by careful selection of a professional staff, thereby ensuring a low attrition rate (Viele, Dodd & Morrison, 1984). Disadvantages of the centralized method are isolation of staff and patients (DeHovitz, 1986) and labeling of the unit as the "AIDS floor" (McGuirk & Miles, 1987).

Dispersal is a second model for providing hospital care to AIDS patients. The various current patterns include: private rooms only (Burda & Powills, 1986); semi-private rooms with other AIDS patients, or private as required by the patient's immune status (Burda, 1986; Jackson et al., 1986); and semiprivate rooms with any patient as indicated by patient status (Burda & Powills, 1986). An advantage of the dispersed method is that staffing levels need not be increased in any one ward, because the AIDS patients (who require more nursing hours) are dispersed throughout the hospital (Burda & Powills, 1986). The patients are assigned to rooms based on the admitting diagnosis. A disadvantage is that staff may be uncomfortable and unskilled at providing the needed care (Cecchi, 1986a; DeHovitz, 1986). In addition, other patients may object to being in a room with an AIDS patient (Burda & Powills, 1986; DeHovitz, 1986; Volberding, 1985). One investigator reported lower hospital stress scores among AIDS patients on specialized units when compared with patients dispersed throughout the hospital (Van Servellen, 1989). The costs and outcomes of specialized units or programs versus dispersal or mainstreaming AIDS patients throughout the institution need to be examined closely.

Another aspect of inpatient care that needs research is the effectiveness of a designated health-care professional to coordinate care of the HIV-infected patient. The role of the Clinical AIDS Coordinator is to assist AIDS patients with their educational and psychosocial needs, identify their support systems, connect them with those support systems, and provide assistance to caregivers in the areas of infection control, in-service education, and patient care. A clinical nurse specialist may function in this role (Morrison, 1987), and some institutions treating large numbers of persons with HIV infection have developed an AIDS resource or consultation team. This approach may be advantageous when large numbers of patients are cared for utilizing the dispersed method. Teams are usually multidisciplinary and include a nurse, physician, infection control specialist, social worker, counselor, chaplain, and representatives from other disciplines as needed (Brock, 1986). The effectiveness of the Clinical AIDS Coordinator and AIDS resource teams needs assessment.

Models of Outpatient and Community Care

Because only an estimated 10 percent of care for patients with AIDS is provided in the hospital setting, the need to evaluate efficient and effective systems of outpatient care is vital (Beresford, 1989). On-site hospice care is being delivered by hospice organizations or under the auspices of hospitals, churches, Department of Veterans Affairs (VA) hospitals, and visiting nurses' associations (Droste, 1987; Jackson et al., 1986; Lutz, 1987; McGuirk & Miles, 1987; Smith, 1987). Care is also provided in long term, skilled, or intermediate care facilities, but facilities that accept persons with AIDS are inadequate in number and designed for elderly women, not young men who may have psychiatric problems and major nursing care needs (Arno & Hughes, 1987; Burda & Powills, 1986; Droste, 1987). Home or hospice care is usually coordinated by a registered nurse (RN), and an RN is on call 24 hours a day (Klug, 1986; Martin, 1986; Schietinger, 1986). The team may also include other individuals, such as a home health aide, homemaker, volunteer, physician, speech therapist, or clergy (Arno, 1986; Baer et al., 1987; Schietinger, 1986). There is opportunity for nurse researchers to identify service needs of infected patients and their care givers at various stages of infection, and to examine costs, benefits, and patient outcomes in alternative settings.

Community AIDS programs have been described in the literature. In Dade County, the South Florida AIDS Network offers home and hospice outpatient care (Rowe & Ryan, 1988). The Shanti program in San Francisco and other AIDS task forces offer volunteers (mainly for psychosocial support), transportation, subsidized housing, residential programs, and food assistance, but the heavy dependence on volunteers in these programs is of concern (Arno, 1986; Jenna & Mount, 1988). A Children's AIDS Program at Boston City Hospital provides both residential and day care for pediatric AIDS patients (Woodruff & Sterzin, 1988), and one model for transitional foster home care for children with AIDS is operating (Zealand, 1989). Their costs and effectiveness have not been systematically evaluated.

When care is provided in the home of the patient, the family, or a significant other, the options include: hospice-terminal care (Arno, 1986; Valdiserri, 1988); home care/chronic care with monitoring for acute episodes (Valdiserri, 1988); public health nursing care; community support services only (Arno, 1986; Carter, 1987; Graham & Cates, 1987); and no outside services. The latter seems to be the most common, as only about 10 percent of infected individuals in the community receive home care or hospice services (Martin, 1986). The optimal combinations for care delivery have not been determined.

In general, the bulk of care for HIV-infected persons is provided outside of the hospital (Schietinger, 1986). Indeed, the trend is for infected patients to receive more care on an outpatient basis and to spend fewer days in a health care facility (Hellinger, 1988). Most infected individuals are concentrated in certain urban areas, but a shift toward rural communities is beginning (Kawata & Andriote, 1988; Sundwall & Bailey, 1988). The expertise developed in the urban areas needs to be shared with rural caregivers.

Another problem is the inadequacy of foster care for children with AIDS. Many of these children are abandoned or orphaned at birth, and many remain in the hospital long after they are well enough for discharge because there are no alternatives for care (Arno & Hughes, 1987; Hutchings, 1988; Klug, 1986). Caregivers tire from the burden of the day-to-day needs of the infected individual, but respite care for caregivers is not readily available (Tourse & Gundersen, 1988; Woodruff & Sterzin, 1988).

Volunteer organizations, particularly from the homosexual community, have been successful in developing out-of-hospital arrangements for some patients, but these systems are not extensive enough to assist many individuals with AIDS, specifically children and IV drug users. Many

AIDS patients have spent up to two consecutive years in acute care hospitals at extraordinarily high expense because of the absence of appropriate facilities for their placement outside the hospital (Arno, 1986; McGuirk & Miles, 1987; Weinberg & Murray, 1987).

Costs of Care

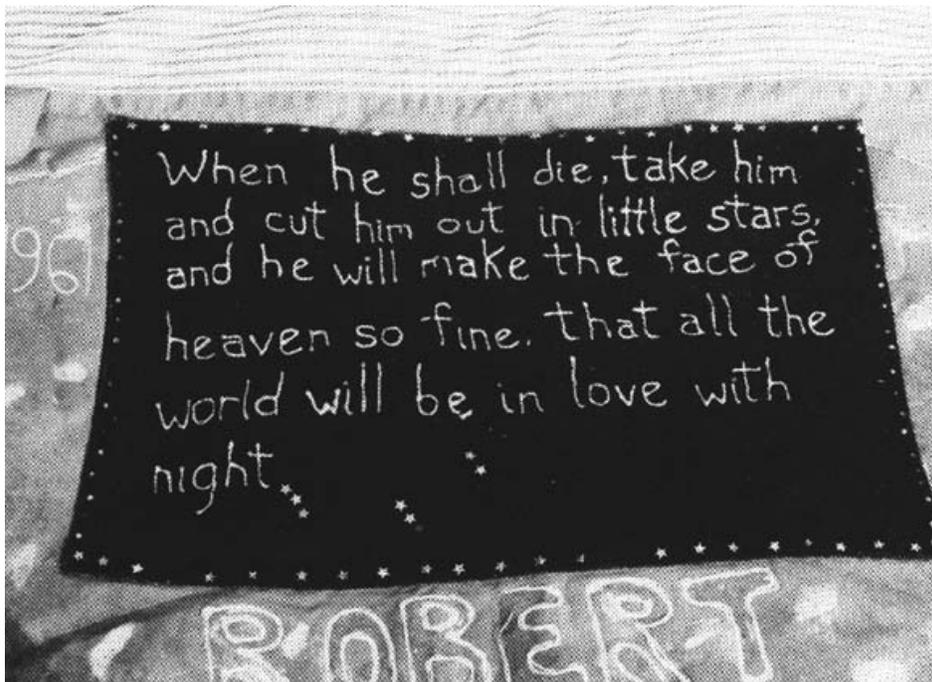
Costs of care vary by setting. Hospital care for patients with AIDS has been estimated at \$800 per day, long-term care at \$300 per day, and home care at \$100 per day (Jenna & Mount, 1988). Over an eight-month period, Trace (1987) studied the costs of hospital care provided to 41 patients with AIDS on several medical units in a large urban medical center. The nursing-care hours per patient during eight months ranged from 3.5 to 1,145 (mean, 176.2); patients with opportunistic infections required the most intensive care. The mean cost of nursing care was \$3,234 per patient; mean hospital charges, \$27,366; mean length of stay, 22.4 days. The author concluded that AIDS was indeed an expensive disease, but that nursing care costs represented only 11.8 percent of the total hospital charges. She did not, however, make any recommendations regarding models of care or the cost implications of methods to deliver care. In Florida, a level of skilled care has been created which doubles Medicaid reimbursement for facilities accepting persons with AIDS (Shapiro, 1988).

Support Systems for Professional Caregivers

Because of the infectious and terminal nature of AIDS, significant stressors are placed upon caregivers practicing in both medical and home care settings (Pastor, 1988). Some specific stressors include: fear of becoming infected (Pownall, 1988; IOM, 1988); the high mortality rate of patients (Morin & Batchelor, 1984); relative youth of many of the critically ill patients; coping with both patient and family stress related to such sensitive topics as drug use or homosexuality (Newman, 1987); and difficulty with organizing complex care (Volberding, 1989).

Little research has addressed methods of providing support for professional caregivers who work with HIV-infected individuals. Blumenfield and colleagues (1987) studied the attitudes of caregivers and reported that half of the nurses surveyed believed that AIDS could be transmitted to

hospital personnel through patient contact, and half reported that they would request a transfer if assigned to care for AIDS patients on a regular basis. Barrick (1988) reported that, among 208 nurse respondents to a mailed survey, there was a significant correlation between their willingness to work with AIDS patients and attitudes toward homosexuality. Rosevelt (1987) surveyed work discrimination as perceived by HIV-infected gay men. However, research demonstrating a correlation between personnel attitudes and actual changes in behavior toward infected individuals was not found.



Research Needs and Opportunities

So little research has been conducted on models of care for HIV-infected persons that the need for data is extensive. Choices must be made to focus research on the most promising care delivery issues. Research is needed to describe the specific health care needs of different groups at different stages in the spectrum of illness, and the influence of family, cultural, social, and geographic differences on these needs and on the use of health-care services. For example, the incidence of AIDS in persons who use IV drugs is frequently associated with poverty, unemployment, homelessness, welfare dependence, prostitution, crime, teenage pregnancy, and other social problems (Fineberg, 1988; Report of the President's Commission, 1988), but the unique service needs of various groups have not been established.

Data are lacking to support an understanding of care and service needs of HIV-infected individuals as they progress through different stages of infection, and as they differ in age, culture, geographic location, economics, social structure, family dynamics, and lifestyle. Similarly, there are few data to demonstrate whether the types of services being offered and the models of care delivery being developed or used are the most appropriate, efficient, and cost-effective for each population. Accommodating the patient's fluctuating needs has been identified as one of the major challenges facing AIDS programs (Afzal & Wyatt, 1989). In particular, research is needed to evaluate models of care that provide continuity across the spectrum of HIV infection. Case management, using nurse case managers, needs evaluation in terms of patient outcomes and cost effectiveness.

The special service requirements of subgroups of HIV-infected individuals need to be identified, including relevant cultural norms to which the providers of services should be sensitive. Although many HIV-infected hemophiliacs are being followed and treated through one of the Regional Comprehensive Hemophiliac Diagnostic and Treatment Centers, the appropriateness of the services to their needs should be assessed. In particular, the needs of spouses of individuals infected by transfusion, including infected hemophiliacs, 5 to 20 percent of whom are infected themselves (Report of the President's Commission, 1988), should be delineated.

The needs of families of HIV-infected children are of concern. In most of these families, the

mother is also infected and may be sick or using IV drugs. Issues include appropriate services to the mother, child, and other family members; the place of foster care for infected children; how the needs of foster parents are being addressed; and service needs of other children in the family who may lose siblings and parents within a short time. For the adolescent, issues that need examination include the adequacy and effectiveness of counseling, testing, follow-up, and referral in sexually transmitted disease clinics, school health clinics, or city health clinics, and the impact of informing a parent of an infected minor.

Needed research on caregiver services includes identification of appropriate services to the mother, infected child, infected adolescent, and other family members; assessment of day care as an alternative for infected children; special needs of day-care facilities for infected children; and assessment of alternative care for infected children, such as transitional homes or family case management.

Multidisciplinary approaches to the delivery of care have been described in both outpatient (Jenna & Mount, 1988; Volberding, 1985) and inpatient units (Jenna & Mount, 1988; McGuirk & Miles, 1987). Some hospitals have designated AIDS units (Jenna & Mount, 1988); others have dispersed infected individuals throughout the hospital and provided care by an interdisciplinary AIDS team (Rosner, Shapiro, Bernabo, & Howard, 1985). Patients with AIDS in the majority of hospitals receive usual care (Kawata & Andriote, 1988). The impact of various models of inpatient care delivery needs to be investigated, particularly with regard to patient outcome and costs. In community settings, the extent to which the volunteer supply can meet needs, and the effectiveness of various programs to support infected individuals deserve study. In addition, the support needs of caregivers should be identified.

Residential facilities are necessary to provide outpatient care or chronic care outside a hospital. Determining how and where residential care facilities are to be established, and how they should be staffed, depends on an understanding of the needs of homeless people with AIDS and their perception of the acceptability of services. Establishing HIV-related services in drug treatment facilities has been suggested as a way to reach IV drug users in an acceptable manner, but only an estimated one-quarter of more than 1.2 million drug users in the U.S. are in drug treatment programs (Fineberg, 1988). Research is needed to identify ways to reach this population, and appropriate services must be designed, delivered, and tested.

Recommendations

Based on the foregoing assessment of research needs and opportunities in "Delivery of Nursing Care," the Panel has made the following recommendations concerning research in this area over the next five years.

- Describe the health care needs of adults, adolescents, and children at different stages of HIV infection: asymptomatic, acutely ill, chronically ill, terminally ill.
 - Identify the special needs of specific groups of infected persons at different stages, particularly minority homosexuals; minority women who acquired infection heterosexually; neonates and families with multigenerational disease; adolescents; HIV-demented patients who are also homeless; infected spouses of hemophiliacs and others infected by trans-fusion; IV drug users.
 - Describe the influence of family dynamics and social, economic, cultural, and geographic differences on the need for health-care services.
- Evaluate the appropriateness, continuity, and use of HIV-related health-care services available in various communities.
 - Evaluate various methods of nursing-care delivery for HIV infected individuals in different settings, particularly case management.

- Compare the quality, cost, patient satisfaction, accessibility, morbidity and mortality, and other outcome indicators in various settings and with several methods of inpatient care, such as centralized versus dispersed placement, age-specific groupings, and use of AIDS coordinators.
- Evaluate the effectiveness of different categories or groupings of health care personnel; for example, AIDS coordinators, AIDS resource/consult teams, and AIDS clinical specialists.
- Identify effective methods for recruitment, retention, and support of nursing staff working with HIV-infected populations.
 - Evaluate the long-term effects of death and dying and the grief process on personnel providing care to persons with HIV infection.
 - Test strategies to promote the use of universal precautions by health care personnel.

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