

# The Culture of Caring: AIDS and the Nursing Profession

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Caring is nursing and nursing is caring (Leininger 1984, 83).

Nurses provide care for people in the midst of health, pain, loss, fear, disfigurement, death, grieving, challenge, growth, birth, and transition on an intimate front-line basis. Expert nurses call this *the privileged place of nursing* [emphasis added] (Benner and Wrubel 1989, xi).

Nursing has always been a much conflicted metaphor in our culture, reflecting all the ambivalence we give to the meaning of womanhood. Perhaps in the future it can give this metaphor, and ultimately caring, new value in all our lives (Reverby 1987, 207).

**T**HE NURSES WHO SPEAK THROUGH THESE quotations all agree that caring is, and always has been, the cornerstone and the quintessence of their profession. It is the key concept of nursing, the vital theme around which the whole field turns. Coded into the notion of caring are the characteristic forms of knowledge and skill, practice, and ritual, the fundamental attitudes and values, beliefs and symbols that define the work that nurses do, its goals, its meaning, and its distinctive culture.

Over time, the world in which nurses work has undergone funda-

mental alterations which have diminished the paramountcy of caring, making it more difficult to sustain on a consistent and continuing basis. Changes in illness patterns, the increasing dominance of technology in medical care, the growth of bureaucratic medicine, and the preoccupation with cost containment in recent years all act to constrain and thwart nurses from meeting what they regard as their foremost and unique obligation to patients. This commitment is succinctly expressed in the motto on the 1989 American Nurses' Association National Nurses' Day poster: "Our Caring Is Constant." In the face of the many circumstances that deter nurses from acting upon their underlying belief that "[c]aring is nursing and nursing is caring" (Leininger 1984, 83), it is remarkable that caring actually occurs so much of the time.

The amount of attention that the American nursing profession has paid to the principles and the phenomena of caring has increased steadily during the 1970s and 1980s. This is especially apparent in the subject matter and discourse of articles, textbooks, monographs, and dissertations that nurse-scholars trained in anthropology, psychology, sociology, education, history, and philosophy have been writing and publishing, and in the statements of educational philosophy and objectives that have been issued by schools of nursing in recent years (Watson 1979, 1985; Benner 1984; Tisdale 1986; Wolf 1988). The current reemphasis on the supremacy of caring in nursing and on its association with the very identity and *raison d'être* of the field emanate from important ideological, intellectual, and clinical developments that are occurring within the profession. Since 1965 the trend in nursing education away from diploma schools and toward colleges or universities has greatly accelerated. In 1965, 80 percent of new nurse graduates were trained in hospital diploma programs; by 1986 less than 15 percent of new graduates were from hospital programs while more than 80 percent graduated from two- and four-year college programs (Aiken and Mullinix 1987). In addition, the contemporary women's movement has had a significant effect on the outlook of the overwhelmingly female membership of the nursing profession (96 percent of registered nurses). The presence in the profession of a critical mass of highly and broadly educated nurses, and of women with raised feminist consciousness, has contributed to a surge of activity directed toward more systematically and fully conceptualizing, describing, and studying the caring core of nursing as, for example, in this excerpt from the writings of nurse-anthropologist Madeleine Leininger (1980, 135, 141-42):

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Caring behaviors, processes, and structures are the most central and unifying focus of nursing practice, and should comprise the major intellectual, theoretical, practical and research endeavors of nurses. . . . Care [should be] studied in a systematic way: a way which explores linguistic usage, epistemologic sources and cross-cultural examples of care and their relationship to nursing. . . . The resulting scientific and humanistic body of nursing knowledge should improve client services by developing an in-depth perspective on the very core of nursing. . . . It will help to validate and explain the distinct nature of nursing.

The preoccupation of the nursing community with the importance of “uncovering” and authenticating what is “embedded” (Benner 1984, 3-4) in their own precepts and practices of care has been accompanied by a drive to distinguish their field from the profession of medicine by which it has been historically dominated, and to liberate nursing from some of the fettering aspects of its inherited definition as “women’s work.” As will be seen, this has entailed an intricate process of trying to attain some distance from what historian Susan M. Reverby (1987, 1 and in *passim*) terms the “ordered to care” tradition of nursing, while asserting its “right” and “desire” to care. It has also involved concerted efforts to demonstrate rigorously that caring attitudes and behaviors such as touching, feeling, and comforting, that are culturally regarded as “feminine” and “soft,” are not only “virtuous,” but have positive clinical effects on patients’ health, illness, and disease that are scientifically explicable.

The same period of renewed interest in caring in nursing has also been a time of crisis for the profession, marked by a serious shortage of nurses, growing discontent among nurses with hospital employment, high rates of “burnout” and job turnover, and a dramatic decline in nursing school enrollments, and in the number of persons planning to pursue nursing careers (Aiken and Mullinix 1987). The enhanced interest in caring is, in part, related to this crisis, which has been increasingly linked to nurses’ perceived loss of control over their practice—particularly over their ability to care for patients in a manner consistent with their deeply held values (Maslach and Jackson 1982; Kramer and Schmalenberg 1988; Kramer and Hafner 1989). It is at this complex juncture in the evolution of the American nursing profession that the interrelated epidemics of human immunodeficiency virus

(HIV) infection and acquired immunodeficiency syndrome (AIDS) have appeared on the national scene.

AIDS is unique among diseases in present-day societies because it is simultaneously acute, chronic, progressive, infectious, and fatal—and also affects young people. At our present stage of medical knowledge, there is no cure for the total collapse of the body's immune defenses that the AIDS virus causes. Despite recent improvements in pharmacologic therapies, for the great majority of symptoms that plague people with AIDS—ranging from the irritating to the excruciating—there are simply no substitutes for the hands-on, face-to-face forms of physical and interpersonal care that constitute the very core of nursing, and in which nurses, above all other health professionals, excel.

Against this background, we will examine the nursing profession's "culture of caring" in detail—its contents, sources, modes of transmission, and the ways that it is brought to bear on the AIDS epidemic. We shall then consider some of the consequences that nurses' involvement in taking care of persons with AIDS may have on the conditions and environment of their professional work, on their collective outlook and morale, and on their relation to the larger health care system.

## Key Components in Nursing Care and Its Culture

Caring for the sick is a queer way to spend one's time, and we act as though it were the most normal thing in the world (Tisdale 1986, 5).

The most basic and palpable aspects of the work that nurses do pertain to the bodies of the patients for whom they care. Nurses attach great significance to caring through touch—even in highly technical health care situations where they refer to these caring actions as "high touch" (Brody 1988, 93).

As Zane Robinson Wolf (1988, 180–230) has shown, bathing patients is one of the most important physical and symbolic foci of these corporeal dimensions of nursing. It is a practice that not only "belongs to the domain and responsibility of nursing," but also contains within it some of the distinctive attributes of the bodily care that nurses render. The explicit scientific rationale for the bath is "to protect the pa-

tient's skin, the first line of defense against disease." It entails handling "private bodily parts," and "dirty," potentially dangerous and contaminating, "infected materials, excreta, such as urine, perspiration, and stool, and secretions, such as mucous, blood, and wound drainage." As nurses recognize, bathing patients is more than an epidermal and hygienic set of procedures. It is also a highly structured, expressive enactment of some of the cardinal values and meanings of nursing care. Skill and grace, comfort and healing, intimate nonverbal as well as verbal communication with patients, respect for their dignity and privacy, and rituals of order, protection, and purification are all combined in the optimally conducted bed bath.

Both in principle and in fact, nursing care is a continuum. It entails an ongoing relationship to patients in all phases of illness and of the life cycle, including dying and death; and it calls for what philosopher Milton Mayeroff (1971, 34, 43) terms "the constancy . . . [of] being with the other." These continuity dimensions of nursing care are epitomized and also sanctified by the "last office"-like procedures that nurses perform when a patient death occurs. ("Even after patients die," Zane Wolf [1988, 139] writes, "nurses care for them, touching them with gentleness.") Bathing the dead patient, laying out his/her body for viewing by the family, and for transport to the morgue, and cleaning the patient's room are constituent elements in what is known as "post-mortem care" in the language of nursing:

The symbolic meaning of the post-mortem ritual rests in the nurses' need to remove the manifestations of suffering, to purify the patient's body and hospital room of the soil and profanity of death, and to gradually relinquish their tenure of responsibility for the patient, given up only as the escort personnel transport the patient to the morgue (Wolf 1988, 139).

In death, as in life, great importance is attached to the role and the meaning of the laying on of hands. To be sure, in their delivery of modern scientific care, nurses do not use only themselves as therapeutic instruments; they bring complex machines and other forms of high technology to bear upon the caring process. They value these advanced modes of care, and have professional pride in their competence to utilize them. But, nurses recognize that absorption in technological medicine can drive a wedge between them and their patients, "dehumanizing" the care that they give, and they worry vociferously about this:

CCU [Critical Care Unit] nurses ran in and out of the room, bringing in supplies as they were needed. Lori, the supervising nurse, stood in the corner with pen and paper, recording every action, while Luce, with her back to the rest of the room, concentrated on the monitor, calling out the rhythms as they came over the screen.

No one was looking at Mrs. Nelson, the scared, dying woman.

The resuscitation stopped as a normal heart pattern smoothly slid across the monitor screen, and Mrs. Nelson again began to breathe spontaneously.

A desire to comfort her engulfed me, and I gently pushed my way to her side. Recognizing me, she started to cry and grasped my hand (Heron 1988, 300).

In common with most of her colleagues, Echo Heron, the critical-care nurse who wrote this, also experienced “a great feeling of satisfaction” when she “removed all the tubes and wires” from a patient’s body, in the first phases of post-mortem care—“as if I were purifying him” (Heron 1988, 239)—and she valued “peaceful deaths . . . unimpeded by the resuscitation technology of the defibrillator, monitor, ventilator, and electrocardiograph” (Wolf 1988, 139).

These sentiments are associated with the perspective on the human body that is inherent to nursing. It is a more holistic conception than the one that underlies the biomedical model. In this nursing view, the body is not an object that is separate from, or external to, the thoughts and feelings, the experiences and relationships, the life history and the “self” of the individuals for whom nurses care as patients. Rather, “the influence between mind and body is [seen as] synergistic and mutual,” and “the body [as] continuous with the person.” In turn, this notion of the body has “profound implications” for the way that nurses approach and care for their patients’ bodies, especially for the “messages of comfort and activity” that they believe they can, and should transmit to patients in this way (Benner and Wrubel 1989, xii, 53).

The nursing outlook not only includes recognizing and responding to the entwined physical, emotional, and social aspects of health, illness, and caring, but also encompasses what nurses refer to as their “spiritual” dimensions. These are the human-condition encounters with new and old life, suffering and tragedy, mortality and death, and with the questions of meaning they elicit that nurses intimately face with patients and their families.

Ideally, a caring relationship with patients as defined by nursing entails a dynamic “turning toward the other” meeting of nurse and pa-

tient, through which the nurse enters and empathically shares the patient's situation and suffering. By being present with patients in this compassionate sense, and using herself, as well as her knowledge and skill, therapeutically, the nurse provides comfort and support to them and to their families; relieves their physical, emotional, and existential distress; promotes their developmental growth and change (and her own as well); and creates a climate in which healing, if not always cure, takes place. "Perceptual awareness" and "discretionary judgment," devotion, trust and hope, courage, respect, and something akin to love for the person who is one's patient are all constituent elements of this ideal model of nursing care and caring (Gaut 1979, 23-24).

Caring about, for, and with patients in these ways includes serving as "health educators" for them and their families—sharing information with them, and teaching them skills that are pertinent to their illness situation and conducive to their well-being. In addition, nurses are expected, and taught, to translate their caring commitment to patients into "patient advocacy" when it is called for:

The nursing ethos of the past, rooted in unquestioning obedience to the physician, has given way to an ethic of advocacy for the patient. The present American Nurses' Association [1985] Code for Nurses, for example, dictates that respect for human dignity and support of the patient's rights to self-determination are an integral part of nursing practice. Furthermore, when patients lack the capacity to decide, nurses are expected to act in their best interests, operating from a patient-oriented rather than a medically-oriented perspective (Theis 1986, 1223).

## Nurses' Socialization for Caring

The science and philosophy of nursing care—its concepts and principles, knowledge and skills, and the attitudes, values, and beliefs that underlie it—are central to the process of professional education. In part, nursing care is taught to them through lectures, in the classrooms, laboratories, and clinics of their nurses' training, and via the textbooks, articles, and manuals that they study en route. The manner in which nurses learn the methods and ethos of caring that are distinctive to their profession, however, is not confined to these forms of ped-

agogy. In fact, it might be said that it is largely through other media that the culture of caring is conveyed to nurses.

Preeminent among these is the way in which nurses are socialized to acknowledge the feelings that their lived-in experiences with patients arouse in them, and to share these experiences and feelings with each other. Coping with the stresses of caring in this fashion is a preferred means of coming to terms with difficult emotional, moral, and spiritual aspects of their work, which nurses are explicitly encouraged, and taught to use:

Health care workers are repeatedly exposed to breakdown, tragedy, and death. Even with the best defenses, the nurse must confront the limits of control, and inevitability of death, and in the case of violence, the very real presence of cruelty. Nurses know through their work that the worst can happen, and this infiltrates and colors one's sense of the world. Health care workers may cope with laughter, bravado, detachment, and elaborate self-protective maneuvers to feel immune to the calamity they confront, but these are temporary "Band-Aids" that can grant only fleeting immunity. In the midst of such "immunity-granting" coping, it is helpful to acknowledge to one's coworkers the pain and threat one confronts (Benner and Wrubel 1989, 376-77).

The nursing profession imparts its cultural tradition of caring to neophytes most powerfully through its participatory mode of teaching them the procedures that constitute the major "occupational rituals" (Bosk 1980) of their field. These are highly patterned, finely regulated practices that are "part of the fabric of the personal-care tasks" (Wolf 1988, x) that nurses perform in their daily rounds. On an unspoken and symbolic level, they contain within them key values and goals that are integral to the identity of nursing and the meaning of nursing care. Zane Robinson Wolf's study of nursing rituals on "7H," a medical unit in an urban teaching hospital, singles out post-mortem care, medication administration, medical aseptic practices, and change-of-shift report as among the most important of these at-once "sacred and profane" aspects of nurses' work (Wolf 1988).

As Wolf observed, despite the existence and easy availability of hospital policy and procedure manuals that detail these practices, they are not generally used in training nurses. Rather, the procedures are taught chiefly by demonstration, and by oral transmission in everyday practice



as well as demonstration contexts. Some of the more symbolic and sacred aspects of these nursing care acts are nonverbally communicated: for example, "the tradition of not crossing the arms of a Jewish patient" (Wolf 1988, 121) in giving post-mortem care. The fact that these ritual-infused acts of nursing are conveyed from one generation to another in a practicum setting, through face-to-face interaction, oral tradition, and structured silence, enhances their conscious and unconscious impact on both senior and junior nurses.

### Social Origins of Nurses and Their Ethos of Care

While we acknowledge the deep influence that their education and clinical experiences have on nurses' socialization in caring, we believe that the social origins of nurses also play a significant shaping role in this process.

The best time-series data available on the social backgrounds of nurses, and some of the attitudes and values relevant to care and caring with which they begin their professional education, are found in the annual survey of entering freshmen in American two- and four-year colleges and universities that has been conducted since 1966 by the American Council of Education-University of California, Los Angeles (ACE-UCLA) Cooperative Institutional Research Program (CIRP). These 23 years of data about college freshmen include within them a population described as "aspiring nurses," (i.e., students planning to major in nursing) who are overwhelmingly female in gender. Compared to the women "nurses," (i.e., those planning careers other than nursing) in the 1988 CIRP freshmen survey, these nurse aspirants have the following sociodemographic characteristics and value orientations that we feel are relevant to their entry into the profession (Astin, Green, and Korn 1987; Green 1987; unpublished data from the Higher Education Research Institute of the University of California, Los Angeles 1989).

The standard indicators of socioeconomic status—parental income and education—suggest that a sizeable proportion of nurse aspirants are products of working- and lower-middle-class families. Prospective nurses are much more likely to come from lower-income families than freshman women interested in other careers: one-third of the nurses

compared with only one-fifth of their nonnursing peers reported a parental income under \$25,000 per year. An examination of the sources of funding for educational expenses on which nurses rely is further suggestive of the economic status of their parents. Compared with other freshman women, nurses are more likely to have received federal grants and loans based on economic need to finance their education; a significantly smaller proportion have received contributions in excess of \$1,500 per year from their parents for college expenses (43.7 percent versus 64.2 percent), and more than twice as many nurses as nonnurses expect to work full time while attending college.

Nurse aspirants also have a lower proportion of parents who are college educated than the nonnursing population: less than one-third of "nursing fathers" compared with more than one-half of the fathers of their nonnursing contemporaries were college graduates. The same pattern holds when mothers' education is considered. The educational status of "nursing parents" is even more starkly revealed by the 1986 CIRP survey data which showed that their percentage was the lowest among all "professional parents," including parents of aspirants to allied health fields and to elementary and secondary school teaching.

The data on fathers' occupations, for the most part, do not provide meaningful comparisons since many of the occupations listed are imprecisely defined. (For example, the category of "businessman" into which a substantial percentage of both "nursing and nonnursing fathers" fall, does not differentiate among managerial, sales, and support positions within the private sector.) By collapsing the lower tiers of the occupational ladder, however, where definitional clarity prevailed, some sense of the differences between the two groups emerges. One-quarter of "nursing fathers" held jobs classified in the survey as skilled, semi-skilled, or unskilled, or were unemployed, versus 14.8 percent of the fathers of their nonnursing peers.

Finally, with respect to their religious orientations, nurse aspirants were preponderantly Christian. Of these, the largest proportion was Catholic (36.9 percent), while Baptist was the next most frequently cited denomination (20.7 percent). More than twice as many nonnurses as nurses reported no religious affiliation.

The same freshman survey has identified a number of attitudinal and value patterns that distinguish nurse aspirants from their nonnurse peers and appear to have some bearing on their prospective entry into nursing:

- Nursing students gave greater support to the life goals of “helping others in difficulty” (83.2 percent versus 66.3 percent) and to “raising a family” (76.8 percent versus 67.5 percent).
- They were somewhat less likely to endorse “being very well off financially” as an “essential” or “very important” life goal, although they more frequently cited “getting a better job” or “making more money” as a rationale for pursuing a college education.
- The nurse aspirants were somewhat more inclined to have attended religious services during the year prior to the survey, while laying less emphasis on “developing a philosophy of life” than the nonnurse population. While fewer nurses rated this item as an “essential” life goal, their embeddedness in the ethos, if not the institution of their religion, may have already provided the philosophical underpinnings that more of their college peers cite as a “very important” life objective.

The extent to which nursing students' social class, religious origins, and value orientations influence their socialization to the culture of caring in nursing is an issue that has rarely been raised, and the answer remains elusive. The virtual and puzzling absence of discussion on this topic by both nurse-scholars and sociologists who observe, study, and inform the profession about its values and attitudes, beliefs, and practices—both latent and manifest—represents a significant void in the literature on the socialization of nurses. The cognitive, technical, and attitudinal aspects of being a nurse are communicated, explicitly and implicitly, through an intensive, highly structured process. But, students do not arrive in professional school as empty vessels, devoid of values, attitudes, and beliefs. Nurses carry into their professional education the constellations of values that their family, social class, and religious origins have helped to shape. The role that these background factors play in the professional socialization process, and the degree of their complementarity to the core value of caring in the nursing profession merits further investigation. Whatever the extent of their impact, we would expect that a change in the social origins of prospective entrants to the profession would alter, in critical and observable ways, the culture of caring.

In addition, these same factors may also help to account for the unusual allegiance that nursing students have to their chosen field. Even as freshmen, they appear to have developed clearly defined career

choices to which they are strongly committed. A comparison of responses of nurse and nonnurse aspirants to a number of questions concerning their "probable" college major and future career plans reveals striking differences. While fewer than 4.5 percent of the student nurses expect to change their major or their ultimate career goal, this was the case for 18.2 percent of the nonnursing freshman respondents. And, given the significant attention which the current and anticipated nursing shortage has received in both the manpower literature and the mass media, it is not surprising that 90 percent of the nurse aspirants expect to find employment in their field of choice. Although these data reflect expected rather than observed changes in career preparation and occupational preference, they are, nonetheless, suggestive of the unusual degree of attachment these nurse aspirants have, so early in their education, to the profession of nursing and the culture of caring in which it is grounded.

## Nursing Care of Persons with AIDS

Because AIDS is a chronic life-threatening illness that has no cure, it is essentially a nursing disease—that is, the essence is caring rather than curing (Fahrner 1988, 115).

Caring for persons with AIDS calls upon the entire range of physical, psychological, social, and spiritual interventions that nurses are characteristically, and, in many respects, singularly educated to provide. It encompasses home and hospice care delivered in the community, as well as acute-care nursing in the hospital. And its most technically proficient and humane forms are predicated on the "compassionate holistic" (Fahrner 1988, 121) conception of care around which nursing's professional culture turns.

The chief physical symptoms and sources of suffering with which AIDS nursing care is concerned, and that nurses attempt to manage and relieve, include pain which is often severe; disabling fatigue and weakness; grave nutritional problems; chronic diarrhea, which leads to numerous secondary problems, including skin breakdown; sensory and perceptual deficits related to neurological involvement; anxiety, depression, and dementia; fevers; and the ever-present threat of infection (San Francisco General Hospital Nursing Staff 1986; Memorial Sloan-Kettering Cancer Center; California Nurses' Association 1987; Durham

and Cohen 1987; *Journal of Palliative Care* 1988; Lewis 1988; World Health Organization in collaboration with the International Council of Nurses 1988). To this appalling syndrome of simultaneous, multiple disease processes that are severe, progressive, and affect virtually every organ system of the body, and to the serious side effects that are engendered by some of the medications used to treat the symptoms of AIDS (particularly opportunistic infections), nurses bring every caregiving skill that they "always use with patients." "Nursing care of acutely ill patients with AIDS does not require a new body of knowledge," they assert (Fahrner 1988, 115). In the sphere of physical care, the nurse must marshal sophisticated observational and assessment skills to identify and evaluate signs of impaired gas exchange and neurological alterations contributing to the patient's respiratory and sensory-perceptual difficulties. This care also relies on such use of practical, time-honored comfort and security measures, as giving patients chicken broth to counteract the metallic taste induced by pentamidine, a drug used to treat pneumocystic carinii pneumonia (PCP); turning and positioning patients and massaging their bony prominences frequently while they are in bed, keeping their sheets wrinkle-free, and lubricating their skin with a mixture of vitamin A and D ointment and mineral oil to prevent skin breakdown; encouraging patients with painful lesions of the oral mucous membrane to take cool, soothing nourishments (i.e., ices, jello, ice cream, malts); and providing patients with calendars, clocks, photographs, familiar objects, signs identifying their room and bathroom, and the like, as ways of contravening central nervous system disease-induced mental confusion, and minimizing the necessity for using restraints. In addition, the AIDS nursing care plans and published descriptions of nursing interventions recommend the employment of "innovative, creative" methods (Fahrner 1988, 118)—notably, alternative pain control therapies (therapeutic touch, relaxation exercises, guided imagery, and visualization), and "holistic approaches to spiritual, emotional, mental and physical well-being to enhance general immune response" (Nurses' Coalition on AIDS as published in California Nurses' Association 1987).

Caring for persons ill with AIDS elicits all of nursing's psychological, social, cultural, and educational expertise, and its spiritual care-giving capacities as well. The young, mortally ill AIDS patients to whom nurses continually minister and relate are not only riddled with many forms of physical suffering. They are also beset by a communicable,

epidemic disease that is greatly feared in the general population, and even among many physicians, nurses, and other health care professionals. It is also a disease that (at the present time in the United States) primarily afflicts "many people whose lifestyles are different from the majority of the society," as the Memorial Sloan-Kettering Cancer Center nursing care plan for AIDS euphemistically puts it. The fact that a large proportion of people with AIDS are homosexual or bisexual men and intravenous (IV) drug users has evoked widespread stigmatizing, shunning, and discriminatory reactions to persons with AIDS, along with the more fearful ones that expose them to isolation and rejection and make them more vulnerable to feelings of shame and guilt. Furthermore, the diagnosis of AIDS can force persons ill with it to reveal their homosexuality or their drug abuse to family, loved ones, friends, and colleagues who may respond with anger, anxiety, fear, or revulsion. In addition, the disease ravages the bodies of those who have AIDS in ways that may drastically affect their self-image and repel others. The extreme weight loss that accompanies AIDS, and the thick, purplish tumors of Kaposi's sarcoma that develop under the skin are among the most publicly visible and disfiguring signs of the disease. And hovering over it all is the fatality of AIDS: the imminent, youthfully premature death that so far has claimed every person afflicted with the disease.

I . . . wish to thank the nurses on 10 East, whose genuine concern and lack of fear made Peter's six hospital visits at UCSD Medical Center bearable. Their excellent care helped us and continues to help so many others. . . . I have an ever-growing admiration for his nurses. Peter is but one of many AIDS patients with [the] problem [of diarrhea with incontinence], but they go about their chores very matter-of-factly and treat him with respect and affection. They come and go constantly, asking how he feels and encouraging him to talk about his feelings. He seems to feel their concern for them, too. When he was admitted yesterday, he went first to the nursing station. . . . He feels very comfortable in their care (Peabody 1986, acknowledgments, 135).

This tribute, written by a mother whose son died from AIDS at the age of 29, testifies to the crucial role that nurses and the care that they render play in helping persons with AIDS, their families, and significant others to deal with their psychic, social, and spiritual suffering:

with the fear and anxiety, anger and angst, the isolation and ostracism, guilt and shame, the change in self-image, the loss of self-competence and self-worth, the sense of helplessness, and of putrefying decay, the sorrow and despair, and the ultimate questions of meaning that the AIDS situation engenders in them. Particularly during the multiple in-hospital stays that AIDS patients undergo, it is the nurses who are not only the most continuous, immediate, 24-hour providers of care in all these spheres, but also the chief coordinators of the kind of holistic, multidisciplinary, collaborative caring that is involved. This nursing-integrated model of care is centered on the patient, in relation to his/her family and significant others. In addition to nurses and medical doctors, it draws into its orbit psychiatrists, social workers, nutritionists, respiratory and physical therapists, clergy, and community-based AIDS services, among others. Along with pain and symptom management, nursing care plans for AIDS emphasize understanding illness from the viewpoint of what persons afflicted with the disease, their relatives, and intimates experience, and also from inside the emotions that it arouses in nurse caretakers. It is a model that includes persons with AIDS in decision making and self-care as much as possible, while enabling them to accept the assistance they need; educating and counseling patients and those close to them about matters vital to coping with the illness and with impending death; and creating conditions that can foster "peace of mind and spirit," through the existential growth both of the persons suffering from AIDS and of those caring for them. These conceptions and dimensions of care, and the values they embody are the foci of the various nursing care plans for AIDS that we have examined. Written in the disciplined and systematic language of the scientific method, these plans are nonetheless full of highly practical and deeply humane prescriptions for nursing care and caring (Becknell and Smith (1975).

## Social Contexts of AIDS Nursing

Nurses care for patients with AIDS in a number of different settings, both inside and outside the hospital. The various organizational contexts in which they work, and the roles that they assume in these milieux, are as expressive of their caring philosophy and convictions as the specific nursing acts that they perform.

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Inside the hospital, acute AIDS nursing care is carried out within relatively small, "designated" or "dedicated" units, as they are known, which are exclusively for AIDS patients, or on regular, inpatient services, where "scattered beds" of persons ill with AIDS are located. Some 40 American hospitals now operate special AIDS units, representing 750 beds in 10 states and Puerto Rico, and the number of such facilities is steadily increasing (Taravella 1989). A model for many of them is the pioneering Special Care Unit of San Francisco General Hospital, opened in July 1983, which was planned by the Hospital's Department of Nursing (Morrison 1987). Some of the social systems, as well as nursing and medical attributes of oncology, burn, and clinical research units have also influenced the conception of specialized AIDS care units. The two types of arrangements for hospitalizing AIDS patients reflect a growing debate regarding the best strategy for organizing AIDS care.

Proponents of dedicated AIDS units point to the overall advantages of specialized units, including staff who are experienced and expert in managing the type and range of problems presented by AIDS patients, and who are able to provide continuity of care over time. Furthermore, staff on special AIDS units become particularly knowledgeable about how the disease is transmitted. As a result, they may more accurately assess and more selectively use isolation precautions, thus giving less expensive and more humane care. The specialized units appear to be more conducive than general hospital units to developing the whole spectrum of required services, integrating inpatient and outpatient care, and involving an interdisciplinary team. In addition, patients may feel less stigmatized and more open in a specialized unit where everyone shares common difficulties and hopes. In specialized units, patients often have roommates who are companions in suffering and sources of support, whereas in other units AIDS patients are often isolated in private rooms. From an educational perspective, specialized units offer nurses, physicians, and other health professionals the opportunity to rotate through the AIDS service and to concentrate on the challenges of HIV infection without the distractions of competing clinical priorities.

The opponents of the concept of specialized units argue (without any confirmation at this time) that the nursing staff will "burn out" more quickly if they are exclusively devoted to the care of AIDS patients, and that the units will pose difficult recruitment problems.



There is also some fear that hospitals with dedicated units will become known as "AIDS hospitals" which will scare away other patients. The possibility that special units may end up isolating and stigmatizing people with AIDS in ways analogous to the situation of patients in mental hospitals has been raised, along with the speculative prediction that, in the long run, this could lead to a deterioration in the quality of AIDS care. Finally, the practical matter of costs has been invoked; unless a hospital can expect a stable and high census of AIDS patients, it is alleged, a dedicated unit with its fixed costs can be considerably more expensive than admitting AIDS patients to whatever hospital bed is available.

Definitive institutional answers to these questions have not yet been reached. But from the perspective of our interest in nursing's culture of caring, it is significant to note that many of the nurses affiliated with AIDS units have volunteered to work in those settings, and that a number of these units have sizable waiting lists of nurses eager to join them. For these nurses, it would seem, some of the most important values, meanings, and fulfillments of their profession are epitomized in this sort of intensive, expert, primary nursing-centered team environment, where the mission is to care skillfully and compassionately for the very ill persons whose fatal conditions cannot be cured in a supportive, holistic, and collaborative patient-and-family-oriented way that involves both the individuals who suffer from AIDS and their caretakers in a therapeutic community. We have seen no evidence to substantiate the thesis that nurses who elect to work in special AIDS units are different from other nurses, either demographically or in their sexual orientation. Instead, we are inclined to believe that nurses tend to be attracted to AIDS and other specialized units primarily because the degree of professional autonomy and support that they are accorded in these settings help them to provide what they regard as quality care.

The activities of nurses involved in AIDS care are not confined to the hospital, but extend beyond it into the homes of persons with AIDS, where public health nurses, visiting nurses, home care nurses, and hospice nurses, among others, play a central role in assessing, monitoring, managing, and treating the "roller-coaster nature of the disease" at all points "along the continuum of [the] illness, from the time an individual is at risk for infection through [its] terminal phase" (Dickinson, Clark, and Swafford 1988, 216).

From the earliest days of the epidemic, nurses have assumed strong

roles in developing such volunteer- and community-based AIDS services, and as care providers within them. For example, "the first meeting of the KS [Kaposi's sarcoma] Foundation, which later evolved into the San Francisco AIDS Foundation, was held in a school gymnasium, and was organized and led by health care providers, including a nurse, a hospital administrator, and a physician, working with two or three community organizers" (Lewis 1988, 307). Nurses have continued to be active in this foundation, which offers community and professional education and counseling services relevant to AIDS, support groups for persons with AIDS, their families, and significant others, and transportation facilities.

Nurses have also been pivotally involved in the Gay Men's Health Crisis, Inc. (GMHC) since this premier AIDS voluntary association in New York City was founded in 1982. As the GMHC has grown in volunteer membership and staff, and expanded its educational, hot line, counseling, support group, home care, case management, crisis intervention, transport, and research activities, nurses—themselves volunteers—have helped to structure, coordinate, and administer these functions. Their input has been especially important in GMHC's "buddies" program. This consists of some 700 to 1,000 volunteers, organized in teams of from 9 to 15 individuals, who help persons with AIDS living at home to manage the daily rounds, by assisting them with house-keeping tasks, grocery shopping, meal preparation, laundry, personal grooming, and the like; by keeping watch over their medical condition; and by providing them with a supportive, caring presence. Each "buddy team" functions under the continual aegis of a nurse, a "captain," and sometimes a "co-captain"; and it meets once a month as a group. Nurses in GMHC not only engage in supervisory and organizational functions; they also do a certain amount of hands-on care as "buddies," case manager partners, and crisis interveners (J.A. Bennett, personal communication 1989).

Anecdotal evidence suggests that a considerable number of nurses are volunteering their free time to care for people with AIDS in home and hospice settings. As Rashidah Hassan (executive director of Blacks Educating Blacks about Sexual Health Issues) explains, "Nurses are drawn to volunteering [because it] allows for personal expression. They're not locked into a system," the way nurses are when they carry out their daily hospital-based work round. As volunteers, nurses "can do hands-on, direct education and . . . physical caring and comfort on their own

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terms" (American Nurses' Association 1988, 23). Above and beyond the gratifying autonomy that nurses experience in volunteering, we find it an impressive confirmation of their commitment to caring that so many nurses have the motivation and the stamina to extend their care giving into their after-work, personal lives.

The several organizations we have mentioned are examples of what has been estimated to be the over 500 agencies related to AIDS that have developed in the United States since the recognition of the epidemic (Lewis 1988). Chiefly in and through such organizations, and both the national and state levels of the American Nurses' Association, nurses have also been involved in policy and political advocacy activities to ensure that financial and community resources are made available to provide skilled, humane care for all persons with AIDS, and to promote continuing public and professional education relevant to the prevention and treatment of the disease.

### Challenges and Stresses of AIDS Care Nursing

This is not to say that American nurses are massively participating in caring for AIDS patients, or in AIDS-associated activities. Nor do we mean to imply that—impelled by their profession's moral commitment to deliver care without prejudice to all those who need it, regardless of the nature of their health problem, social or economic status, or personal attributes—all, or even most nurses are unambivalently ready to respond to the suffering and danger that AIDS has brought in its wake. Various surveys of nurses' attitudes toward AIDS and caring for patients with the disease that have been conducted in different regions of the country indicate that, in common with many physicians and other health care professionals and workers, a sizable number of nurses feel great reluctance about caring for AIDS patients, because of their fear of infecting themselves or family members, their disapproval of homosexuality and discomfort about relating to homosexual men, their strong negative sentiments about intravenous drug use and users, and because of the relentlessly fatal outcome of the disease (Douglas, Kalman, and Kalman 1985; Blumenfield et al. 1987; Wertz et al. 1987; Colombotos 1988; van Servellen, Lewis and Leake 1988a, 1988b).

Even those nurses highly committed to caring for persons with

AIDS, and experienced in doing so, admit that there are aspects of taking care of AIDS patients that they find "devastating." Most frequently mentioned in this connection is the lethality of the disease:

DONNA GALLAGHER: . . . There's futility in this disease. We have never been faced—at least not in my lifetime—with the kind of epidemic where everyone experiencing it is probably going to die. People die of cancer but you have a phase where you can really cheerlead them on and hope that they get by. With AIDS, there's really not a cheerleading phase.

We all feel the pressure that no matter what you do, or how hard you do it, or how fast, you probably won't save anyone. That's a very big obstacle that we have to get by as nurses.

JOAN L. JACOB: When someone asks me, "What's the hardest thing for you?" I say, "Grieving. There's not enough time."

I lost 125 patients in about a year and a half. When I am reviewing charts, maybe 50 at a time, I say to myself, "They are all dead." Then it hits me and I begin to grieve anew for each one. . . .

We are not prepared for this. But how can you prepare people for something this devastating? (Bennett 1987, 1150-55).

Nurses also experience stressful difficulties in caring for AIDS patients who are IV drug users, that are not as likely to be mitigated over time as the anxieties which many of them initially bring to the care of AIDS patients who are homosexual. In contrast to the gay persons ill with AIDS who are predominantly white, with above-average educational and income levels, drug users with AIDS in cities like New York are mainly Hispanic or black, with no more than a high school education or less, whose incomes have often been reduced to poverty through the psychic and social, as well as the financial costs of getting and taking drugs. While AIDS is increasingly becoming a disease affecting blacks and Hispanics, the racial and ethnic composition of the nursing profession remains overwhelmingly white. In 1988, 91.7 percent of the over two million licensed registered nurses in the United States were non-Hispanic whites (unpublished data from the National Sample Survey of Nurses, U.S. Department of Health and Human Services 1984, 1988). In this respect nurses and the patients with AIDS for whom they are caring are culturally dissimilar. Nurses have not written about these sociocultural differences between themselves and their patients. They do report difficulties, however, in establishing good nurse/patient

relations with IV drug users who have carried into the hospital context distrusting attitudes and manipulative behaviors characteristic of street drug culture (Friedman et al. 1987).

### The Redeeming Significance of Caring for Persons with AIDS

Written in the tradition and rhetoric of personal witnessing, testimonials composed by nurses have appeared both in the nursing literature and in the print media. They express a quickened, reconverted, and recommitted relation to the primary values and ultimate meaning of nursing and nursing care. AIDS and nursing those afflicted with it are not only portrayed in their particularities; they are also viewed as "writ large," collective representations of disease and illness in general, and of the "legacy" of "car[ing] for others the way we would want to be cared for if we were sick." Beyond that, they are linked to societal issues of justice and equality, and of individual rights and communal responsibility, and to transsocietal, universalistic principles of dignity, love, peace, and panhuman oneness.

I have just spent 12 hours in a darkened room with a man who exudes fury and despair. Disagreeable, rude, scathingly critical, he lies wrapped in blankets because he is always cold, an angular bony heap, too weak to hold a newspaper without effort, too dejected even to try, shut down from whatever life he has left. Refusing to complain, he hugs his misery to himself like a cloak of thorns.

He has AIDS. . . .

Ordinarily, I scoff at knee-jerk responses to AIDS, those panicky overreactions vastly disproportionate to the facts. But after my first night of caring for someone with AIDS, I plunge straight into paranoia, tumult, confusion.

The barrage is a shock. I went into this nursing with open eyes. . . . I know how [AIDS] is transferred and how it is said not to be transferred. I understand that people who suffer from this terrible illness have a damn good reason to be angry, frightened, depressed. I even took a course that taught me how to deal with all of this. But, in fact, I am not prepared. . . .

As I sit at my desk, I think about the man to whom I am scheduled to return tonight. . . . Does it occur to him that I have come to

him out of choice? In my imagination, I say to him, "I am here because I believe that every human being has a birthright to stand whole and proud of who he is and, in times of trouble, to be cared for with love and respect." . . .

I climb into bed with a cup of hot milk. I am calmer, more reflective. But the negative feelings aren't so easily banished, nor should they be. . . . I remind myself that wearing gloves does not have to be inharmonious with concern, compassion, courtesy. . . . Further, my responsibility is to seek guidance and support for myself so that I can continue to do this work and do it well (Worth 1988, 60, 62).

. . . I entered Michael's room and introduced myself. I stretched out my hand—as I had done in many other rooms—but Michael turned away and kept his hands hidden beneath the bedcovers. "I have AIDS," he said rather tersely. "You've got to wear a space suit to come into this room. Didn't they tell you?" "I'd like to shake your hand and talk to you awhile," I offered. "I'm not afraid. Are you?" Michael turned toward me in disbelief. Slowly he pulled away. Tears appeared and rolled gently down his thin face. "This is the first time my skin has touched the skin of another person for 12 days," he wept. . . .

During one year with Michael, we formed the AIDS Nursing Task Force, an *ad hoc* group in which we shared knowledge about AIDS. The "space suits" disappeared from our wards, and with the confidence and courage we now felt, . . . we were able to share our new insights with parents, physicians, dieticians, and housekeepers. . .

Michael is gone, but he left a powerful legacy: through him, we have been able to see the simple truth of caring—to care for others the way we would want to be cared for if we were sick (Brock 1988, 46-47).

Although the language of such testimonials is not explicitly religious, either in referring to a deity or in a denominational sense, they are infused with the Christian ideas of *caritas*. (The historical fact that nursing originated in Christian religious orders, and the contemporaneous fact that the majority of present-day American nurses are Christian, among whom many are actively identified with their religious tradition, probably contribute to the importance of *caritas* in the caring ethos of the profession.) Another notable feature of these testimonials is the degree to which they turn around an in-depth encounter with a particular patient, who has become for the nurse/witness, and in many cases for her/his colleagues, too, the personification of the moral and spiritual, as well as medical import of AIDS.

## Reflections on the Long-term Effects of the AIDS Epidemic on Nursing

What kinds of enduring effects, if any, will the advent of AIDS in its epidemic form, and nurses' response to it, have on the profession's view of itself; on the way that it is regarded by others (physicians and other health professionals, patients and their families, and the public at large); on the social system of the hospital in which nurses are the chief and most constant providers of around-the-clock care; and on the multiple extrahospital and community settings where nurses do their work as well? Deciding how to address these questions—what to look for and look at—is an intricate matter; venturing predictions of this sort is highly speculative at best. Experts of various kinds who have attempted to forecast what the long-term impact of AIDS on nursing will be have expressed divergent opinions. On the one hand, for example, in stating their concern about the availability of an adequate number of nurses to care for AIDS patients, the Presidential Commission on the Human Immunodeficiency Virus Epidemic (1988, 23) commented:

The acuity of disease of persons with HIV infection, the complexity of their physical and psychosocial needs, the high fatality rate, and the fear of exposure to HIV, along with low salaries and understaffing in many facilities, create a potential for considerable stress, burn-out, turnover, and dramatic projected shortages for the delivery of HIV patient care in the near future. On the other hand, as we have seen, many of the nurses who have spearheaded the profession's involvement in AIDS care are convinced (to quote one of them) that "it has taken the AIDS epidemic for us to develop a vision for the future and realize our true potential as a profession": AIDS offers us many opportunities for growth. . . Working with AIDS, as with other illnesses, can be extremely trying and stressful. Although it constantly tests our abilities as professionals and individuals, it does not have to be depressing. We can find unlimited fulfillment in our work with these patients, their families, and their significant others and walk away knowing we have done our best. AIDS continues to test our society; those of us who accept the challenges and face the issues head on will find a personal fulfillment and satisfaction that we have never known before (Morrison 1988, xviii-xvix).

Our perspective on the ramifying consequences that AIDS will have for the nursing profession is both more tentative and more complex than either of these extreme positions.

It appears to us that a critical mass of the nurses working in the field of AIDS are, indeed, having an extraordinary opportunity to use their profession's "particular ability to care" (Witcher 1987). What is more, they are exercising it in a way that bridges what historian Susan Reverby describes as "the dichotomy between the duty and desire to care for others and the right to control and define this activity" with which nurses—and others who do what our society considers "women's work"—have long contended (Reverby 1987,1). Since there is presently no cure for AIDS in sight, it is only caring, and caring of precisely the sort that nurses are uniquely trained to perform, that makes a difference. As a result, in most AIDS care settings, nurses are not only the chief dispensers of care; they also play central roles in directing and coordinating it. Furthermore, nurses are gaining recognition from physicians, as well as from patients and their families, for their caring attitudes and competence. This is especially true in the designated AIDS units that hospitals have created:

The nurses on the AIDS unit [at Montefiore Medical Center in New York City] say their job satisfaction is related to being treated more respectfully than usual by physicians. . . .

Dr. [Gerald] Friedland [medical director of the unit] agreed that AIDS has altered the traditional relationship between doctors and nurses. Nurses, he said, adapted more easily to situations where patients were comforted rather than cured.

"They were trained that way and we weren't," Dr. Friedland said. "My generation of doctors were all of the belief we could cure everything. We have become more modest" (Gross 1988).

In these respects, it would seem, at least in AIDS contexts, that the role of caring, and the distinctive relation of nursing to it have been receiving significant interprofessional and institutional acknowledgment. What is more, the kind of care that is being responded to in these ways exemplifies the knowledge and skills, attitudes and values that the leading "philosophy and science of caring" spokespersons of the nursing profession espouse, and are trying to convey to the new generation of students entering the field. The AIDS situation has even helped to loosen the tight association of nursing care with "women's work," through the conspicuous number of male nurses who are engaged in the clinical care of AIDS patients.

Particularly in some of the cities where the AIDS epidemic has



reached crisis proportions, it has been a catalyst for organizational change and innovation in the delivery of AIDS care. For example, the San Francisco General Hospital has developed what is nationally considered to be a model system of comprehensive, multidisciplinary, physical, and psychosocial care of patients with AIDS, that emphasizes outpatient management, and integrates it with inpatient services and also home care—working in close collaboration with a network of community agencies to achieve this (Volberding 1985). Nurses, both male and female, have been instrumental in designing this system, and in implementing it through the plethora of care-giving and care-administering roles they fill within it. Many of the organizational features that characterize these new AIDS service programs incorporate elements long sought by nurses, and have been recommended by the series of expert panels on nursing that were convened during the 1980s (Institute of Medicine 1983; National Commission on Nursing 1983; U.S. Department of Health and Human Services 1988), but which have rarely been put into practice by health care institutions. The dedicated AIDS units are among the most noteworthy of these.

But will these changes that, at one and the same time, improve care for persons with AIDS and the working situation of nurses, persist in the settings where they are already in place? Will they spread to other facilities and communities? And will these AIDS-induced patterns and models of care influence other parts of the health care system through a sort of spillover effect? For a variety of reasons, our prognosis is guarded.

To begin with, some of the factors that have been essential to the favorable developments that have occurred in AIDS care and nursing only exist in certain locales. One such precondition has been the presence in particular areas of many gay persons who “have built a wide range of political, social, and community organizations,” which have “served as an infrastructure” for their collective response to AIDS (Friedman et al. 1987, 202). Within this framework, in cities like San Francisco and New York, they have played a crucial part in creating an ensemble of community-based services for AIDS patients, and in linking them with both the inpatient and outpatient care provided by hospitals.

The priming role of the gay world in fostering new forms of AIDS care is relevant to another phenomenon that could eventually undermine what has been achieved. Up until now, gay males have been the main risk group for AIDS in cities such as New York and San Fran-

cisco; but the number of new HIV infections among gay males has significantly declined. The number and proportion of intravenous drug users with AIDS, however, has been increasing. As we have indicated, the majority of drug users with AIDS are poor, black, or Hispanic, with low educational levels, whose ability to organize themselves to deal with AIDS is seriously hindered by "individual, subcultural, and societal obstacles" (Friedman et al. 1987, 215). Will the care organizations that have developed in response to AIDS be willing and able to absorb this influx of disadvantaged and disenfranchised persons into their midst? And if so, will this bring about other creative changes in the system of AIDS care; or will the challenging demands involved progressively lead to its erosion and deconstruction?

In the long run, in particular cities where the growth in AIDS patients continues, more of whom are poor and underprivileged than in the past, this may plunge the already overburdened health care system of the community into a grave state of crisis. Such is currently the case in New York, as a mayoral panel of health experts appointed to examine the AIDS situation in the city reported in March 1989:

There are 1,800 AIDS patients in hospitals in New York City. Most hospitals are reporting that they are filled to nearly 100 percent capacity. . . .

Acquired immune deficiency syndrome "is tearing at the very heart of the city," the report said.

"AIDS is not only the city's medical crisis of our times," the panel added, "but threatens to become the city's social catastrophe of the century.

"AIDS did not create the crisis, but it now represents the final straw, which threatens the well-being of the entire system and the availability of health care for all New Yorkers."

Without remedial action, the panel warned, "the whole proud New York City system of patient care, biomedical research and medical training, generally viewed as the best in the world, will swiftly deteriorate" (Lambert 1989).

In appraising the possible long-term effects of the AIDS situation on care and caring, nurses and nursing, and on the relations between them, what also needs to be considered as a limiting factor is the relative "invisibility" of the new models of care, and of the singular role of nurses outside the AIDS-circumscribed universe. For all of their real advantages, for example, this may turn out to be one of the major draw-

backs of designated inpatient AIDS units. Their relative insularity within the hospital, along with their specificity, may make them too inconspicuous to affect the hospital as a social system.

What is more, many nurses who are engaged in AIDS care feel that what they are doing and what they know are not being adequately seen or heard, either inside or outside the hospital:

DONNA GALLAGHER: One obstacle is that nurses in this field are invisible. You hear physicians being interviewed about the crisis and even about patient care issues. But do reporters interview nurses?

JOAN L. JACOB: Unfortunately, [nurse] clinicians are so busy that they don't have time to go out and be heard. Our energies at the end of the day are in going home and healing our wounds.

GAYLING GEE: For such a high-profile disease, nursing certainly has kept a very low profile. As much as we do, we need to talk about it more (Bennett 1987, 1151-1152).

Nurses are perhaps most conscious of still another factor likely to constrain the long-lasting influence that AIDS can be expected to have on the health care system, and on the recognized place of nurses within it. This is what might be called an historical forgetting process. Most people are unaware that many of the challenges and issues that AIDS presents are not unique, first-time occurrences. This nonawareness carries with it a lack of acknowledgment of the important care initiatives that the nursing profession has taken in the past:

PAT McCARTHY: Everything is so reminiscent of what happened in oncology 20 to 30 years ago. AIDS is a new disease but it has raised the same old issues. When there were no specific community resources for people with cancer, nurses had to insist that existing community resources be used to treat people with cancer or to offer their home care services to people with cancer. Well, now we're telling the community agencies, "You may not realize it, but all your services are going to apply to people with AIDS, too." We're in the position of convincing people that they need to take on one more disease category (Bennett 1987, 1152).

When that day arrives to which we all look forward, and AIDS has become a disease that is more within our power to control, will the part that nurses have played at this juncture in its history be recalled? And

whenever it is that we reach the point of being able to cure, as well as prevent, AIDS, will we continue to appreciate the lessons about the importance of caring that it has taught us, and of the embodiment of the skills, the values, and commitments that it entails in the work and the culture of the nursing profession?

We hope so. And we hope, too, that what we have written here will contribute to the remembering.

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