

Volunteer Visitors for Patients with AIDS

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AIDS is the most feared and dreaded disease in our lifetimes. Its explosive growth, its strange symptoms, its deadliness, and the mystery of its origins and future course all set AIDS apart from familiar diseases.¹

In the early days of AIDS when there were only a few AIDS patients at Bellevue Hospital Center and other hospitals across the country, a small volunteer program was established at Bellevue to provide socialization and comfort for these patients. In February 1984, seven volunteers were trained to visit three to ten hospitalized adult patients; recently 35 volunteers made 450 visits within a month to many of 130 patients with AIDS.

This paper describes the development of the Volunteer Visitor Program at Bellevue Hospital Center in the hope that the program can be a model. It was born of necessity in a hospital that was in the forefront of caring for AIDS patients even before the medical manifestations of the disease were clearly defined. These seriously ill patients had complex medical and psychosocial problems which professional staffs were trying to solve. Equally important, many patients were isolated, lonely and frightened and needed sensitive human contact. People from the community concerned about persons with AIDS came forward as volunteers to participate in the formation of the Volunteer Visitor Program. This was one of the first structured hospital programs with volunteers specifically visiting AIDS patients and assisting beleaguered staffs who provide their care. It was clear from the start that volunteers make a difference in socialization, in struggles with fear and

hope, and in the total case management. Perhaps other institutions or agencies planning to utilize volunteers with persons with AIDS can benefit from the trials and errors, problems and successes encountered at Bellevue.

BACKGROUND

Bellevue Hospital has cared for New York City's residents for more than 250 years. It has provided medical treatment since its origins as an almshouse and has turned no one away regardless of race, color, creed, nationality, or income.

One of the largest municipal hospitals in the country, Bellevue Hospital Center today has 1200 acute care beds and extremely active Outpatient and Emergency Services. It is affiliated with New York University Medical Center, whose clinical and research staffs have contributed not only to the care of patients but also to understanding of their diseases. NYU physicians have been deeply involved with AIDS research and treatment.

The Volunteer Visitor Program began in 1983 at Bellevue Hospital after Mead Bailey, a Bellevue chaplain and board member of the AIDS Resource Center, suggested that there were caring community people who wished to provide companionship to hospitalized persons with AIDS. The Aids Resource Center (ARC) is a nonprofit organization in New York City formed to meet the growing needs of Persons with AIDS (PWA's) which provides housing, support services, and pastoral care. ARC was a pioneer in developing services which were not available to PWA's and their families.

Joan A. Dumont, Director of Volunteer Services at Bellevue Hospital Center in New York City for eight years, developed several hospital volunteer programs to meet emerging inner city health needs, including the program described here. Active in local, state and national professional organizations, she was a founding member of the New York State Association of Directors of Volunteer Services (in Health Care Facilities). She is a member of the NYC Mayor's Voluntary Action Center Task Force on AIDS and on several advisory committees for agencies serving sick children. She is presently a consultant in volunteer management, and her interest lies in assisting programs utilizing volunteers to help AIDS sufferers or ill children.

Chaplain Bailey, already seeing PWA's as patients at Bellevue, was keenly aware of the lack of supports and services for them. He seized the opportunity to bring the resources of a community agency into a public, teaching hospital to try to meet some of the needs of patients with this baffling disease who were often alone and ostracized.

Planning for this program took several months. The AIDS Resource Center worked with the directors of Social Work and Volunteer Services and the chaplains to lay foundations within the hospital. First, approval to proceed was required from the hospital administration. Since Bellevue is committed to providing medical care for the sick poor, this was easily obtained. (Some hospitals were not supportive of such programs since they did not want to acknowledge the presence of AIDS in their facilities or the fact that special care was required.)

Bellevue had already formed a hospital-wide AIDS Task Force comprised of representatives of departments which had staff working with PWA's. Active members included physicians, nurses, health educators, social workers, administrators, and staff from the Infection Control, Personnel, Patient Advocacy, Methadone Maintenance, Child Life, Therapeutic Activities, Food Service, Housekeeping, Employee Health Services, and Community and Public Relations departments. Task Force members were encouraging and helpful in establishing the volunteer program. They were aware of the multifaceted approaches needed in this crisis.

The Task Force also assisted in promoting educational efforts so that all hospital employees, no matter what their jobs, were informed about this new and frightening disease. More specific information was required in many instances for better care of PWA's. In addition, it was necessary for staff to learn how to work with volunteers as well as patients in these new circumstances.

A program protocol, description of volunteer duties, and plan for training were developed. These initial steps as well as supervision, support, arrangements with staff on the units, recruitment, screening, and assignment were carried out by the directors of Volunteer Services and Social

Work with help from volunteers. The first volunteer, one of the original ARC group, had difficulty keeping in touch with the other volunteers due to his employment commitments. The second volunteer was a seminary student, also from ARC, who was able to be more involved. He worked closely with staff and volunteers and was invaluable in forming the foundations of the program. As the program grew, the directors needed more help with many functions; and a part-time coordinator, who later became full-time, was hired. The two departments continued to jointly manage the program and oversee all aspects.

THE PROGRAM

Volunteer Visitors at Bellevue visit adult patients with AIDS or AIDS Related Complex during their hospital stay. These patients are usually critically ill, have little hope of recovery, are faced with profound medical and social problems, and may have few family or friends. A visit might include a bit of conversation, listening to what may be troubling a patient, bringing a sandwich or soda, running an errand, or simply sitting and holding a patient's hand.

The program coordinator assigns volunteers to visit patients and works with the volunteers and staff to assess the needs of patients. In addition, he is responsible for the organization of all aspects of the program, is in constant contact with the volunteers, and conducts training and support meetings. He has expanded services for patients and broadened the role of volunteers now that he is full-time. As noted above, at first volunteers had assisted in coordinating and training functions. However, responding to the need for more and consistent staff, the Auxiliary to Bellevue provided the half-time salary for a professional coordinator which was supplemented by a grant from Chase Manhattan Bank to make the position full-time.

Thirty-five volunteers made approximately 450 visits to 113 of about 130 hospitalized AIDS patients in the month of May 1988. Since the program began in 1984, men and women, artists, clergy, members of church groups, professionals, people in business, students, retirees

and others who are not working, PWA's, people of all ages, both gay and nongay, have come forth. Although patients were primarily male homosexuals in the early days, now more than 80 percent of hospitalized PWA's at Bellevue are minority, intravenous drug abusers, and an increasing number, perhaps 10 percent, are women. Many of the volunteers are white, middle class, who require information about substance abuse and minority cultures in addition to discussion about ways to relate to disenfranchised people.

Recruitment

The first group of volunteers was referred to Bellevue through the AIDS Resource Center, which continued to help with recruiting, particularly with seminary students and clergy for whom AIDS was a new and compelling issue. Recruitment information and program descriptions periodically are sent to churches, community groups, and local papers. Articles in magazines and newspapers about the plight of PWA's have stimulated people with the desire to help to come in on their own. AIDS organizations and community volunteer centers have referred candidates, and word of mouth has brought PWA's as well as friends of patients and other volunteers. Recruiting of more minority volunteers and appropriate recovered substance abusers is indicated.

The flow of candidates has been slow but steady. During the past year, 75 potential candidates were trained in five training sessions. However, a continuous supply of new volunteers is essential as there is turnover due to burnout, even with good support and opportunities for taking time off. More than 150 volunteers have taken the training; 35 are currently active while several others are on leave.

Screening

Candidates for this program are not easy to assess. People who are caring, compassionate, sensitive to others, have a good sense of self, can listen, can advocate, and possess a sense of humor have emerged as having good potential as Volunteer Visitors.

There is a vast range of applicants, each with different reasons for wishing to vol-

unteer and each with an unusual personal story. A widow in her 70s wanted to help because she was indignant that "nobody cared about people sick with AIDS." A married couple, an actor and actress, volunteered because they had known people with AIDS through their work. A writer concerned about PWA's was also looking for experience to help him decide upon a career change. Others have had loved ones who have died of AIDS.

All candidates were screened upon first telephone contact by the Director of Volunteer Services who later interviewed them. Although a second interview originally was conducted by the Director of Social Work, now this responsibility lies with the program coordinator. It is important to note that the screening process continues through the training, at which time any problems related to the candidate's joining the program perceived by either the program staff or the candidate are resolved. A candidate who is unsure may, with more knowledge and self awareness, find the impact of involvement too great and decide to leave. Or, as in only a few cases, the program staff will suggest another assignment, perhaps not in direct contact with AIDS patients, at Bellevue or another organization.

Training and Support

All volunteers take the training in two four-hour sessions prior to being assigned to visit patients.² The training in June 1988 was the fourteenth program. Modifications and additions have been made through the years, reflecting the acquisition of new information, changes in the patient population, and volunteer feedback. Although individuals come in with varying amounts of information and diversity of experience, all must take the Bellevue training in order to ensure a baseline of knowledge.

The first training session provides an introduction to AIDS, including infection control, psychosocial aspects of AIDS, profiles of drug abusers, spiritual issues, and the role and responsibilities of the volunteer. During the second meeting, a PWA discusses living with AIDS, and participants explore their feelings and attitudes about issues such as illness, death and dying, minorities, homosexuality, and

substance abuse. Questions and open discussion are encouraged. These sessions are productive and promote the expression of true feelings and responses. The motivation of the participants creates a positive and dynamic tone that contributes to their learning.

A vital component of this program is the monthly support meeting. Conducted by the coordinator, there may be speakers to provide new information and perspectives but there is always opportunity to share in discussions about patients, issues, and emotions. These meetings are meaningful for the volunteers and also give the coordinator insights and information about patients and the operation of the program.

The "buddy" process by which most volunteers start their visiting is a valuable part of education and support. Usually, a new volunteer will accompany an experienced volunteer in one or two visits to patients, learning not only about visiting but how to find one's way around the hospital since the patients are on many different units. These first visits ease the way for new, nervous, and eager volunteers.

Operation of the Program

All candidates, no matter where they may be placed at Bellevue Hospital Center, must be medically cleared before they can volunteer. Specifically, they must have had a medical checkup within a year prior to serving and be cleared for hepatitis, rubella, chicken pox and tuberculosis.

Upon completion of medical clearances, volunteers obtain a jacket and identification which they must wear whenever they are serving in the hospital. It is important that the Volunteer Visitors are clearly identified to signify primarily to patients that they are visiting because they choose to do so, an important message in light of all the fears about AIDS. Also, they are often spotted by staff and asked to give additional assistance.

The coordinator first meets with patients, asking them if they wish visitors. Each volunteer is assigned one to four PWA's to visit and continues to visit the same patients while they are in the hospital. Some patients may have several

volunteers who visit at different times but are part of an assigned team. The volunteer team will often meet together or talk on the telephone in order to discuss each patient's needs. The use of teams with team leaders relieves the coordinator in a variety of ways but he is readily available for the volunteers.

A typical visiting experience for a volunteer with four patients might be as follows:

Patient A is new and recently diagnosed. He says he wants a Volunteer Visitor but is not feeling well enough to talk, and he is wary. The volunteer stays only a few minutes and says that he will be back another time.

Patient B had been discharged the previous day.

Patient C is in her room and pleased to see the volunteer whom she has known for many months during her hospital stays and clinic visits. There is easy talk about things they share as their friendship has grown. The patient reports that she will be released to an apartment with nursing coverage through the efforts of her social worker and the volunteer.

Patient D was difficult for this volunteer. An intravenous drug user who initially was moody and skeptical about the Volunteer Visitor's reasons for spending time with him, he had recently appeared glad for the visits and was able to talk. The volunteer had brought in a milkshake, which he had stored in the refrigerator in the Nursing Station. The Volunteer Visitor scheduled this visit at the end of the day so that he could spend unlimited time with the patient. Patient D was not in his room. He had died that morning.

The foregoing synopsis of 90 minutes of volunteer time produced a wide range of emotions for this volunteer and for which no one can ever be fully prepared.

It is obvious that volunteers in this program must be able to deal with diverse situations and feelings. Many bring extraordinary experiences and exceptional strengths. When asked in the initial interviews about knowledge of or contact with people who are substance abusers, some volunteers report that they, themselves, are recovered alcoholics or drug abusers. They have benefitted from "Twelve Step" or other recovery programs

and continuous support from their groups. They want to be Volunteer Visitors because they are grateful for their own recoveries and want to pay back. They bring with them an established pattern of helping others.

The Volunteer Coordinator plays a key role in providing support to all volunteers, particularly in their time of stress or sadness. His sensitivity and knowledge of the volunteers are vital not only in matching volunteers to patients but also in supporting their continuing relationships with patients. He is the resource and referral person who tries to obtain solutions for the problems patients present which, since the volunteers are not visiting as professionals, must be handled by appropriate hospital personnel.

The Volunteer Visitors have become part of the team at Bellevue. They handle themselves well, working along with various professional staffs, and are respected for their willingness to assist in many different ways as well as for their dedication to the patients. They also share with their peers in support meetings, giving and gaining, and contribute much of themselves at other times. Recent examples of their expanding activity are the formation, with supervision, of Alcoholics Anonymous, Narcotics Anonymous, and other support groups for patients as well as groups for adolescent children of AIDS patients.

A BROADER VIEW

Many aspects of this program are unique, reflecting the unusual characteristics of the disease compounded by the problems of the inner city. Patients have numerous medical problems and little hope for a long life. Their medical conditions change as do their related psychosocial problems and behavior. Hospital personnel and volunteers are called upon to help PWA's deal with pressing life and death issues, some of which contributed to their contracting the disease.

This program has been described with emphasis upon structure and management with several points that should be highlighted. Volunteers have given PWA's extra care, companionship and a personal touch for which paid staff lack the time, and sometimes interest or ability. A com-

munity agency brought volunteers to a public hospital which was unprepared to try to deal with this emerging crisis. The hospital responded quickly and gradually built a sound volunteer program. The strong cooperative efforts of two hospital departments in the successful management of a program with issues that involved many patients, different staffs, and volunteers are also important to note. The rallying of forces in crisis, even in a large, unwieldy institution, has been spectacular.

Today, the Volunteer Visitor Program is established with a four-year track record. The number of patients keeps on growing with changes in the demographics of the population. Volunteers will continue to make a difference, but more and varied groups should be recruited. They will need more education about the problems of the patient population, about minorities, about people who are disenfranchised and have been in trouble with the law. The needs of patients with AIDS are so numerous and complex that volunteers will be asked to assist with a range of tasks, some of them new, from leading AA and NA groups to providing escort services, home care, and office help. There is much that volunteer administrators will need to do to support these efforts.

Volunteers have made a significant impact on the care of patients with AIDS at Bellevue Hospital Center. They have provided the extra human resources to enhance patient care, to give hope to people who are in discomfort and despair, and to make life a little better for many individuals, even if for only a very short while.

APPENDIX A
VOLUNTEER VISITOR PROGRAM
Training Sessions

Topic	Instructor
Session I	
Introductions	Director of Volunteer Services
Psychosocial Aspects of AIDS	Director of Social Work
AIDS 101	Health Educator
Substance Abuse	Substance Abuse/Health Educator
Death and Dying	Program Coordinator
Session II	
Living with AIDS	A Person with AIDS
Spiritual Aspects	Chaplain
Patient Advocacy	Patient Advocate
Hispanic Concerns	Staff from Hispanic Agency
Role Play and Discussion	Program Coordinator

FOOTNOTES

- ¹Peter Hiam. "Failing the AIDS Test," *Harvard Magazine*, March-April 1988, p. 35.
²See Appendix A.

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In October 1987, The Volunteer Visitor Program at Bellevue Hospital Center received an award from the New York City Mayor's Voluntary Action Center for the service of its volunteers to patients with AIDS.