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AIDS: LEGAL, PUBLIC, AND PASTORAL IMPLICATIONS

SR. JOANNE LUCID, B.V.M.

AIDS is not the first communicable, incurable, fatal disease to challenge the compassion, the creativity and the courage of the community. It probably will not be the last. I am grateful to be invited to be with you and I would like to acknowledge you for your commitment because you are making a difference in our work, particularly in offering care and compassion, working against discrimination, and for the protection of a person's human rights. I am the supervisor of the Archdiocesan AIDS ministry and I work closely with thirty churches of other denominations.

When we began our Archdiocesan program, which was officially approved in June, 1986, the State of Minnesota had fifty-six cases of AIDS. Currently we have 366. It has been very interesting for me to watch the development of this program because now we have 110 Catholic volunteers who are supporting persons who have been affected by the disease. That is a great growth. All of these people have been trained through the College of St. Thomas.

The program has three parts: the first is education which we know is extremely important with respect to our clergy and ministers who are actively involved with their parishes as pastoral associates; the second part would be the actual pastoral counseling and the ministry. This is the heart of the matter. What we have done in our area of the country, because of our concern that there has been a gap, that the church's presence has not been clearly identified to those persons with AIDS, is to work very closely with our clinics. So we are associated with all the infectious disease doctors and they offer to their patients, upon diagnosis, the support of the Archdiocese. This is the way we come into close contact with so many persons. Otherwise, there was a gap in our services. Therefore, it is through the doctor who offers our support that the contact is first made. Now there are other ways that we receive referrals, but this is how about ninety percent of our referrals come—from the doctors.

The third part of our program is to network with the state health department and other community organizations as they offer support and

resources to the persons who have been affected. So AIDS is presenting to us an ultimate challenge. We are, right now, in the seventh year of an epidemic. This is medicine's challenge for the decade, if not for the century. Since the onset, this epidemic has raised equally demanding ethical questions that must be resolved if treatment is to be given in a humane and caring manner. In general, the ethical questions are not new. However, they arise more frequently in AIDS cases because of the terminal nature of the disease, and because of the youthfulness of the persons with this disease, factors which contribute so much to the tragedy and shock for families. But, also, to die from AIDS is a particularly terrible way to die. At the time of diagnosis persons may feel strong and healthy. As time passes he or she faces progressive weakness and disability, loss of body function and control, severe weight loss and, in two-thirds of the cases, dementia occurs as the virus attacks the central nervous system.

Repeated hospitalizations bring demoralization, particularly at times when the hospital staff may not be as well trained and may be inadequate to make responses to some of the concerns and issues that the patient has. We know of certain problems so we have been supporting our medical staff, our nurses, by offering them support groups, individual counseling and so on, due to the burn-out problem addressed earlier.

Mathilde Krim, a prominent New York physician, wrote in a 1985 *Hastings Center Report*: "AIDS clearly represents a worldwide threat to public health. The challenge to scientific and medical institutions is an enormous one, but so is the challenge to the psychological, ethical, legal and social fabric of society." Then she added, "How these particular wealthy Western nations deal with the threat of AIDS will measure to what extent we can call ourselves civilized."¹

What is at issue here, then, are fundamental human questions. Questions which will call us to the core of our humanity. The essential issue is, how do we respond to persons with AIDS and how do we respond to AIDS as a human disease? There are many, many issues that we could deal with around the question of AIDS. What I will be doing is offering just a sampling of these issues, not exhausting any of the possibilities present. They all call for justice, compassion and care.

Obviously, the first issue would be discrimination. The second, confidentiality. The third is the conflict between individual rights and social welfare. Fourth, what treatment to provide for AIDS patients in the terminal phase of their illness.

My comments will focus on the issues and concerns in doing ministry within the context of AIDS. The comments are an attempt to examine

¹ Krim, *Aids: The Challenge to Science and Medicine*, HASTINGS CENTER REP., Aug. 1985, at 7.

how the context of such a ministry of pastoral care is shaped and to explore specific responses a diocese might make when considering pastoral ministry. AIDS brings awareness of death's reality. Underlying any approach to ministry in the context of AIDS is a recognition that we are addressing people's fears and concerns which will ultimately involve them in more than the disease itself.

This disease brings people face-to-face with two of the most powerful and enduring forces in their lives: death and sexuality. The reality and power of death in our lives is unavoidable; regardless of attempts to study, to analyze, and to understand it, it still remains incomprehensible. Often, persons with AIDS confront with great intensity the reality of their death and, at the same time as they are coping with that, they are dealing with the feelings of alienation, in some cases, from their church community, from society, and even from their families.

For a moment, consider the mixed emotions for a person with AIDS who knows, at present from a medical standpoint, there is no treatment or cure. Life expectancy following diagnosis of AIDS may be less than two years. At the same time, that person also knows of the intense research that is being conducted at this time. So people with AIDS are often caught between despair and hopeful optimism which is emotionally wearing on them. Many people have the fear of dying alone, of being abandoned by their friends and family. One gentleman who went to San Francisco last week told me that he has lost sixteen of his friends who have died from AIDS. He himself has AIDS. So the reality is not a vague psychological apprehension he is experiencing; he is experiencing too often the painful reality of what the meaning of this illness has in his life.

Let us focus now on the person deciding to be tested. What goes into such a decision, who do you tell about this decision, where do you seek support, what does it mean to you to hear the words, "HIV positive"? Often a description of this is like a hurricane of emotions for a person, a whirlwind. How does one maintain oneself in his work environment knowing he has AIDS? I am suggesting here the sensitivity we will need to have for our employees who have tested positive and are maintaining themselves in the dignity of their work but are always under a great deal of pressure and tension.

The ethics of appropriate care—and this is another question for the dying patient—has been thoroughly explored in recent years. There are two problems here: the first relates to the doctor-patient relationship. Some doctors have suggested they should be talking to their patient about life maintenance support systems within seventy-two hours of a patient's first hospitalization. This can be well done, but some doctors are also asking for pastoral support around this topic because it is such a difficult discussion to have with a young patient in his first hospitalization. Such a discussion can often lead to a breakdown in the rapport be-

tween doctor and patient.

Another issue to be noted is scarcity of outpatient resources. How can the needs created by this illness and disability be met in a fair and just way? AIDS poses a problem of justice. Many other diseases pose equally difficult challenges for us, but the problem here is if we make AIDS the key focus, there might be discrimination against homosexual persons and drug abusers. We could be discriminating in a budget toward certain groups of people.

A very important concern are the poor and homeless people. We also need a greater outreach to the Black and Latino communities. This is a great concern to us. Members of such communities often come to our hospitals and clinics when they are most sick. They have not been going for testing and our education has not been sufficient for them. This is a place where the church's ministry could reach out and we will need support in order to do this.

I am suggesting in pastoral ministry to people with AIDS that we become their advocates. People are asking us to be their advocates. Whatever the setting, pastoral ministries should be prepared to deal then with a variety of manifestations of despair and depression. Some people have a fatalistic approach to their illness and become suicidal. There will be issues of hopelessness, feelings of abandonment, isolation, guilt and anger. There will be opportunities for families to work toward reconciliation and support. As pastoral ministers we need to recognize and to address them as best we can and utilize the resources of the community in counseling family support and grief groups to work together with other churches to support the community. It is almost like we need to do a good public relations job.

In conclusion, I would like to read a letter I received from a mother several months ago. I invite you to listen so that you can stand within the context of someone's loss and grief:

Many of you did not hear from me last year but I want you to know your cards and letters were wonderful gifts, opened with anticipation, read with delight and displayed with heirlooms.

Dave was seriously ill. Though we prayed with hope, he and we knew it would be his last Christmas. Each item of tradition, each act of preparation was handled with care, caressed with tenderness and filled with bittersweet memories. January 31, 1988, Dave died of AIDS, a debilitating, dehumanizing, insidious illness with an incubation period winding back through an individual's life to an undeterminable time.

Although ill for many months, he was not diagnosed until May 1986. At that time it was his decision to be public about his illness. There was no question in my mind that his decision was right. Despite his weakened condition and the pain, he made himself available for research purposes, he talked with teams of doctors and reporters and was part of a television

documentary.

His determination to fight to the last breath proved courage and determination beyond my comprehension. Hopefully, you will never be closely involved with this illness. But if you know of someone who is, reach out with friendship and compassion for the individual and the family. People with AIDS desperately need affection, care, emotional and physical and sometimes around-the-clock attention, the mental diversion of phone calls and short visits, . . . and prayers and expressions of love and hope.

I am in contact now with several families whose adult children have died or are seriously ill. The lack of support from friends and family is appalling; part is due to their fear of scorn and ridicule and part is due to the insensitivity of people who could be in a position to be of help. Life is fragile. Do express your feelings to those close to you, give thanks for friends and family and let each person know their worth. Share joys and sorrows, accomplishments and disappointments.

This mother is now a leader of one of our support groups. She is supporting about four other families. In this ministry, I have become aware that those who have been ministered to in the beginning of our program are now becoming ministers to others. That probably makes a better description of how ministry ought to be done; it is done best by those who have been through the experience.