AIDS: Toward a Compassionate Response

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AIDS evokes powerful feelings, often manifestations of fear, among health care providers. To effectively treat patients with AIDS, occupational therapists must acknowledge and reconcile their personal feelings. One way to formulate a compassionate response to patients is to understand the meanings that we give to AIDS, meanings that shape our interpersonal behaviors. Restricted meanings—that the disease constitutes death, sin, crime, war, or community division—place the person with AIDS at risk for compromised care. Recognizing the limitations of these meanings can free therapists to find other meanings that inspire compassion.

O ccupational therapists must acknowledge personal attitudes that might interfere with their care of persons with acquired immunodeficiency syndrome (AIDS) (Holland & Tross, 1985). Once they become self-aware, therapists can “recognize the person with AIDS as an individual” and thereby enhance care (Denton, 1987, p. 429). A compassionate response to persons with AIDS requires therapists to recognize the powerful feelings that are associated with highly contagious and mysterious illnesses. These feelings, often manifestations of fear, inhere in the human condition.

This paper explores the universal fears associated with AIDS in an effort to foster a compassionate response among caregivers. Because my purpose is to encourage humanistic responses, I have cited narratives that clarify both the feelings that AIDS evokes and the responses that these feelings can shape. I have included the views of fictional characters because I believe that they poignantly highlight the painful reality of AIDS.

AIDS: Emotional Responses

AIDS evokes powerful emotions with significant consequences. Surveys have revealed homophobic responses among care providers (Douglas, Kalman, & Kalman, 1985). The fear has been so significant that persons with AIDS have been refused medical treatment (Plumeri, 1984). Even when treatment is provided, 32% of the physicians and nurses surveyed in Douglas et al.’s study agreed that “in the hospital, patients with AIDS receive inferior care when compared to patients with other illnesses” (p. 1310). Douglas et al. identified a “constellation of affective responses including fear, disgust, anger, discomfort, and aversion” that health care providers may experience when treating AIDS patients (p. 1309). These responses compromise care. Because epidemiologists predict that the AIDS epidemic is just beginning, we need to develop resources to grapple with uncaring emotional responses (Baer, Hall, Holm, & Lewitter-Koehler, 1987).

Affective responses shape interpersonal behaviors: “The social stigma associated with the contagion aspect causes altered behavior in others, including avoidance of physical and social contact” (Holland & Tross, 1985, p. 761). Because persons with AIDS are often shunned, health practitioners become, by default, part of a small circle of significant others remaining to provide essential care. The circle of caring persons shrinks as the patient with AIDS requires additional care:

AIDS will be a measure upon which we may calibrate not only our medical and scientific skill but our capacity for justice and compassion. (Treichler, 1987, p. 264)
AIDS, including the following: Treichler (1987) assembled 38 beliefs about given the multiple meanings we associate with this disease. Treichler (1987) argued that “AIDS is simultaneously an epidemic of infectious illness and of meanings: both epidemics are equally crucial for us to understand” (p. 268). Meanings are multiple because AIDS exists at a point where entrenched beliefs about illness, suffering, and death intersect (Treichler, 1987).

These beliefs, often metaphors, create affective connections that particularly threaten the care of persons with AIDS.

Sontag (1977) felt that “it is hardly possible to take up one’s residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped” (p. 3). She suggested that a person encounters prejudice when ill from any disease whose etiology is unknown and “overlaid with mystification” (p. 84). Metaphors often become vehicles for the insufficiencies and anxieties of a culture, particularly “our anxieties about feeling” (Sontag, 1977, p. 84). Throughout her text, Sontag pinpointed the source of our anxieties: the fear of contagion. Fear of contagion compromises social interactions. When a person is ill, he or she is confined, exiled, or shunned; encounters with others are often awkward. Sontag further argued that “any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious” (pp. 5–6). One is isolated when ill and this isolation breeds problems both with relationships and the sense of oneself as an intact person.

One fictional character’s description of the worldview held by isolated lepers powerfully communicates the depersonalization that can occur with shunning and isolation. Koolau, a leper in London’s (1909/1965) story, describes the compromised sense of personal self among his peers: “They were creatures who once had been men and women. But they were men and women no longer. They were monsters” (p. 39).

This fear of contagion that prejudices social interactions dwells in the hearts of well and ill, individuals and communities, and caregivers and patients alike. The fear surfaces metaphorically. Honesty, consideration of the various metaphors we have accepted may help us to understand the uncaring feelings we would like to shed. We must believe that we can formulate compassionate responses, that we can move beyond lurid metaphors to helpful ways of caring. This process, however, may not always be easy. Tisdale (1986) wrote,

I suspect that easing the suffering of others is always inconvenient. To do so one must stop deflecting the pain, stop the evasion, take the nose up from the ground. (p. 9)

It remains for us to take our noses up from the ground, as it were, and to scrutinize our metaphorical understandings of AIDS.

AIDS Metaphors

Ross (1986) identified five AIDS metaphors. She argued that when we think of AIDS, we most often understand it as death, sin, crime, war, and community division. Each of these metaphors carries feelings that
threaten to compromise caring responses because each minimizes the value of the patient as a human being. Each metaphor derives power not simply from a fear of AIDS but also from a reservoir of fears associated with other diseases that have plagued mankind. To fully understand these metaphors and to mediate a more compassionate response, we must face the longstanding fears that ground each of them.

AIDS as Death

AIDS means death; the danger of this metaphor is that caregivers will perceive persons with AIDS as already dead, thereby making it easier to withhold care and treatment (Ross, 1986). Powerful fears of dying permeate stories of epidemics and AIDS. Hearing these stories can clarify our deep-rooted impulse to distance ourselves from those who are dying.

A character in Ferro’s (1985) novel about AIDS calls death an “abstract notion . . . not real, not imminent” (p. 159) until it is made concrete by a diagnosis such as that of AIDS. We prefer to remain distanced from death—to maintain its existence as an abstract notion. Another fictional character, a gay detective in Hansen’s (1987) mystery, describes the response to persons with AIDS: “Everybody in their life deserts them. Like it was the plague. Leprosy” (p. 16). The person with AIDS has “the gay plague . . . and his death sentence is proclaimed” (Hansen, 1987, p. 36).

A gay character in Fierstein’s (1987) play justifies his fear: “Being scared is smart. You have to be scared. You’re supposed to be scared. You’re not normal if you’re not scared. Everybody’s scared” (p. 33). Peabody’s (1986) rhetorical question, the question of a mother whose son is dying of AIDS, focuses her fear: “How long can it go on, senseless death after senseless death?” (p. 199). Her question is particularly poignant. She first fears her son Peter’s meaningless death, then she fears that she will fail to help him die meaningfully:

Once he decides it’s over, I’ll have to find a different strength—the strength to help him die, to let him go, to say the right words, to touch him when he wants to be touched and not when he doesn’t. (p. 94)

The task was hard for Peabody who believed, as many of us do, that “in the huge unnaturalness of the world the most unnatural thing is the death of a child” (p. 19).

The fear of death includes fear of the death process and fear of the loss of personal meaning. Fear grips those who are dying as well as those who stand by; everyone struggles for meaning in the face of death. A man dying of AIDS in Sontag’s (1986) story, “The Way We Live Now,” describes the powerful forces that he feels: “The fear rips through me, it tears me open,” and alternately, “it presses me together, squeezes me toward myself” (p. 50). This opening and closing to death, the readying process, is filled with fear. The responses of those who are standing by reflect similar openings and closings. One friend feels opportunity: “We’re learning how to die” (p. 51). Another friend reflects, “I’m not ready to learn” (p. 51). A third friend regrets that people treat the dying as if already dead:

They’d begun talking about him in a retrospective mode, summing up what he was like, what made them fond of him, as if he were finished, completed, already a part of the past. (p. 44)

Peabody (1986) identified the typical response to persons with AIDS:

Most of you will abandon them . . . leave them to die alone, terrified and despised. First, you can’t accept their homosexuality, and next, you can’t face dying and death. (p. 60)

Peabody understood the response when she saw it in her dying son. Even Peter, himself dying of the disease, had problems dealing with the AIDS-related death of friends: “The impassivity is a wall, not insensitivity. Once again, it is his defense against the terror and fear of his own death” (p. 193). Dying represents, after all, the loss of everything.

The fear of death is powerful and evokes deep-rooted responses. When AIDS comes to mean death, the person with AIDS signifies death as well. To equate AIDS with death is to invite the human responses of distancing and flight from the ill person, who has come to represent the loss of everything.

AIDS as Sin

Ross (1986) felt that the metaphor of AIDS as death led directly to the metaphor of AIDS as punishment. Although AIDS claims innocent victims (e.g., hemophiliacs, babies, elderly women, and nuns), gay men and drug users with AIDS are “sinners on their way to illness” (p. 16). Punishment and guilt are deeply associated with AIDS.

The particular horror of some diseases conjures up images of a supernatural force wielding punishment. As Tuchman (1978) wrote, “The apparent absence of earthly cause gave the plague a supernatural and sinister quality” (p. 104). She also wrote,

To the people at large there could be but one explanation—the wrath of God. Planets might satisfy the learned doctors, but God was closer to the average man. A scourge so sweeping and unsparing without any visible cause could only be sent as Divine punishment upon mankind for its sins. It might even be God’s terminal disappointment in his creatures. (p. 103)

Horrible diseases suggest horrible causal agents. Certainly the dreadfulness of AIDS permeated Peabody’s (1986) description of her son’s condition:

Peter has recurrent thrush and herpes proctitis, and in AIDS, the fungus and the virus can invade other parts of the body at
any time—lungs, intestines, eyes, brain—anywhere. He has undiagnosed, subacute encephalitis (inflammation of the brain); constant, undiagnosed diarrhea; increasing fatigue, loss of weight and energy; and an undiagnosed and uncomfortable ear congestion, nasal discharge, and heavy cough. He has also lost his previous immunities to such diseases as measles, chicken pox, and mumps. And, of course, he can always get pneumocystis again, lymph gland malignancies, various exotic parasitic diseases, and Kaposi's sarcoma. (pp. 108–109)

Our horror escalates with the realization that those suffering from AIDS are “mostly young men, used to being independent and self-reliant” (Peabody, 1986, p. 178). A fictional young man with AIDS describes the psychic pain that he experiences: “Occasionally panic arrives with fatigue, like an exhausted old man leading a sobbing child hysterical with fear” (Ferro, 1988, p. 55).

Psychic pain among ill persons is compounded when well persons defend against horrifying diseases by affixing blame. Ill persons, such as Koolau the leper, already ask, “Why? Why should the wholeness of that wild youth . . . change to this?” (London, 1909/1965, p. 55). Any response that blames the individual cannot be helpful. One gay character in Johnson’s (1987) Plague laments,

Isn’t that what Jerry Falwell and his friends are always saying? I mean I must hear several times a week on the TV that I’m going to go to hell for getting this disease—and of course, for being queer. (p. 86)

The message communicated by the metaphor of sin is that those who contract the disease deserve to die. Peabody (1986) empathized with a young man who was judged sinful and thus was rejected:

I wept, too, for his other pain—the pain of his mother’s rejection . . . she, a Bible-toting fundamentalist, insisted that he repent of his sin—so that he would be saved—and again loved. What a hypocrite. If the essence of Christianity is unconditional love, how can these fervent disciples of Christ make their love conditional? (p. 110)

The metaphor of sin presents a world in which illness is desired. To see AIDS as punishment is to agree that the person with AIDS is a sinner; this perspective is judgmental and virtually precludes a compassionate response.

AIDS as Crime

Ross (1986) cautioned against identifying illness with the enemy lest we risk sacrificing persons to the aggression and defensiveness inherent in war. The disease—the enemy—is embodied in a person whom we must not sacrifice (Ross, 1986). The armamentarium against the AIDS enemy is impressive:

At 8:00, the pharmacist finally appears, carrying two big, brown grocery bags of medicines. He explains them and Peter understands completely. He will still be on 600 milligrams of Dilantin and 200 of Tegretol daily as anti-seizure treatment. Two drugs to treat the tuberculosis-like MAl have been eliminated as ineffective, but he will still take ansamycine, clofazime, isoniazide, and pyridoxine. Chlorimazole lozenges are for the oral thrush. Metamucil, Lomotil, and Tylexol with codeine are for diarrhea control, and Alternagel is for the abdominal cramps and pain he has had recently. Multivitamins with iron are for nutrition, as is the low-fat diet of 2,800 calories daily, devoid of all dairy products except yogurt. (Peabody, 1986, pp. 160–167)

The intensity of the medical battle escalates in response to pleas from persons who are ill. Persons with AIDS believe in the battle. A character in “The Way We Live Now” (Sontag, 1986) argues that “all you have to do is to stay healthy for another year or two and then there will be good treatment, real treatment” (p. 45). The main thing is to “keep in shape,” to fight (p. 45). Peabody (1986) described the struggle against AIDS in warlike terms:

AIDS is a constant warfare, an unending siege. The patient is like a small, weakly defended country surrounded by mighty powers. It fights fiercely to defend itself from invasion, but its weapons are few and primitive inadequate. (p. 221)
In *Second Son* (Ferro, 1988) Mark warns that the battle is too intense; harsh treatments sacrifice persons:

"It's the nature of hospitals," he insisted. "[The treatments] are all too strong. Too gross. It's been like that from the beginning. People all die." (p. 151)

Those caught up in battle can lose sight of the individuals for whom the war is being waged. Mark experiences a negative exchange over an experimental treatment. The doctor is brisk and clinically detached. Mark finds this loathsome but realizes that "the clash of a cold medical personality—detached, skeptical—with the fearfulness of victims aggravated by illness, is inevitable" (p. 60). The fighting caregiver risks destroying much personal territory while eradicating the enemy.

Although warfare attacks the enemy, it also defends protected territory by isolating and containing enemy forces. The person with AIDS becomes an evaded enemy. In *Second Son*, Bill, sick with AIDS, notes that "everything that comes into the room [bears] a red diagonal stripe—for destruction—slashed across it" (Ferro, 1988, p. 662). His lover, Mark, asks the nurses if this measure aims to protect Bill or everyone else. Masks and gloves constitute wartime garb. Fear that the enemy might not be contained is pervasive. Marion, a character in *Safe Sex* (Fierstein, 1987), remembers the hospital staff's fear of her husband: "And he was so sick... I was sure he'd die right then. If not from the illness then from the hospital staff's neglect. No one wanted to go near him" (p. 99). Fear plagues property owners. A realtor says, "I'm afraid of what my eyes show, the way I watch him, with too much intensity, or a phony kind of casualness." (p. 51). Another friend says, "I don't know what to say, I think I'll feel awkward, which he's bound to notice, and that will make him feel worse." (pp. 42–43).

Fierstein (1987), in his book's dedication, described the power that AIDS has in compromising the homosexual community: "AIDS has poisoned the joy of affection. It has banished the spontaneity of loving. It imbues lovers with guilt, strangers with distress, and victims with shame." A character in Fierstein's play articulates the loss—"Never holding. Never having... they want to. They used to. They can't anymore." (p. 12).

Each of the four metaphors previously discussed contributes to the creation of the fifth: a pervasive sense of a community divided. The boundaries of demarcation are clear. The person with AIDS is dead, no longer part of the living community. The person with AIDS is a sinner, no longer part of the community of those who are good or saved. The person with AIDS is a criminal against whom the community of good citizens must be vigilant. The person with AIDS is an enemy who must be eradicated by a community of dedicated fighters.

To cling uncritically to these metaphors, to respond to the person with AIDS as if he or she were dead, a sinner, a criminal, an enemy, or an outcast because of the disease, is to risk diminishing his or her personal status. To cling to these images is to further risk depriving him or her of compassion. We need alternate images that can help us to formulate caring responses.

**Beyond Metaphors: A Compassionate Response**

This discussion has thus far explored restricted meanings that can compromise care. Stories hold...
more than lurid metaphors, however, and, in fact, can give us images that inspire care. I hope that the following stories can facilitate a process of turning toward the possibility of a more compassionate response, a first glance that may lead to a deeper consideration.

Camus (1947) presented illness on a community scale in The Plague. Although he depicted compromised care, he also described healthy social interactions among the inhabitants of the city of Oran. This story of plague contains numerous parallels to AIDS. There are abundant references to the confinement and shunning predicted by Sontag (1977). After the public's first acknowledgment of the plague, "isolation of sick members of their families in special wards at the hospital" begins (Camus, 1947, p. 50). Isolation breeds altered relations with Dr. Rieux: "For the first time the doctor feels they are keeping aloof, wrapping themselves up in their malady with a sort of bemused hostility" (p. 57). Measures are taken to ward off contagion: "The residences of sick people are to be shut up and disinfected; persons living in the same house are to go into quarantine" (p. 60). Quarantine extends to the entire town with the following telegram: "Proclaim a state of plague stop close the town" (p. 61).

The isolation from loved ones causes the townspeople to "act as if they have no feelings as individuals" (Camus, 1947, p. 64). They eventually begin to evidence diminished feeling. With more and more deaths, Oran becomes "a victim world, secluded and apart" (p. 98). Camus pointed out the strangeness of "how the [streetcar] passengers all tried to keep their backs turned to their neighbors ... the idea being, of course, to avoid contagion" (p. 113). In restaurants "the customers spend several minutes methodically wiping their plates" (p. 114). The plague has "gradually killed off in all of [them] the faculty not of love only but even of friendship" (p. 171). People crave human contact but "can't bring themselves to yield to it, because of the mistrust that keeps them apart" (p. 184). A neighbor may, after all, "pass the disease to you without your knowing it" (p. 184). Ultimately "in this extremity of solitude no one can count on any help from his neighbor; each has to bear the load of his troubles alone" (p. 71). The plague severs ties.

Camus (1947) balanced his powerful presentation of confinement, exile, shunning, and solitude, a situation markedly like those seen in stories about AIDS, with an equally compelling portrayal of healthy relationships and compassionate responses. He showed, despite the fear of contagion, "a need for friendly contacts, human warmth" (p. 54). Families resist removal of their loved ones: "They lock and bar their doors, preferring contact with the plague to a parting" (p. 85).

The plague causes people to reflect about relationships. Imposed isolation and exile create for many a remorse over past interactional lapses. There is self-reproach for "having troubled too little about [the absent one's ways] in the past" (p. 70).

The plague softens hearts. Strangers care for each other in Camus's kingdom of the ill. The town's Plague Chronicle attempts to "keep up the morale of the populace" (p. 113). Volunteers work alongside Dr. Rieux. Nothing is considered heroic about the volunteer effort; it represents "common decency" (p. 154) and it is "merely logical" (p. 126). Plague victims stand together: "No longer are there individual destinies; only a collective destiny, made of plague and the emotions shared by all" (p. 157). Rieux describes the human response: "What's true of all the evils in the world is true of plague as well. It helps men to rise above themselves" (p. 119).

Though it seems to Rieux that his only alternative in the face of all the loss is to "tighten the strangehold on his feelings and harden his heart protectively" (p. 178), he establishes a close friendship with Tarrou in which "they are conscious of being perfectly at one" (p. 240). When Tarrou is contagious and dying, Rieux commits to caring: "My mother and I will look after you" (p. 263). As Tarrou lies close to death, Rieux, clasping him, "gives him a look of affectionate encouragement" (p. 267). Rieux's loss of Tarrou is a loss of peace; there can be no armistice "for a man who buries his friend" (p. 269).

The plague forges tenderness. The same people who sit back to back on streetcars do care. They care about the dead who are denied a decent burial. Little groups of people "toss flowers into the open trailers for a man who buries his friend" (p. 269). The Plague Chronicle emerges not as death, sin, crime, war, or divided community, but as one of life's challenges well met. These are images that can inspire caregivers.

Two modern plays about AIDS, The Normal Heart (Kramer, 1985) and As Is (Hoffman, 1985), depict AIDS at both the community and personal levels. Kramer's characters feel the shunning that Sontag
(1977) said is associated with mysterious illnesses. Mickey identifies AIDS as “some sort of plague” (p. 40). Because the disease is plaguelike, gays are shunned by heterosexuals and other gays. Ben says it's because “when they get scared [people] don’t behave well” (p. 42). Despite the shunning, there are those who stay and care, as happens in The Plague. Emma, the physician, is asked if she worries about contagion. She replies, “Well, I’m still here” (p. 91). Ned’s lover, Felix, has AIDS. Ned says, “I’m afraid to be with him; I’m afraid to be without him” (p. 81). Ned stays in spite of the knowledge that he will risk contagion and perhaps lose Felix.

Hoffman’s (1985) play presents an evolving response to fear. Rich’s brother can initially touch him only on the back for fear of contagion (p. 14). Later, however, he goes into Rich’s hospital room to say, “I came here to see if I could help you” (p. 79), and they hug. Many people respond to Rich by saying, “Don’t touch me!” (p. 17). This happens so much that Rich speculates that “they have a separate AIDS section in the cemetery so I don’t infect the other corpses” (p. 92). Rich asks his lover, Saul, “Aren’t you afraid I’ll infect you?” to which Saul replies, “Yes, I’m afraid” (p. 19). But Saul stays and “takes him in his arms” (p. 43). He reassures Rich: “I’ll take you as is” (p. 91).

Each of these plays presents the fear of AIDS as well as a fearless caring for persons with the disease. Neither of these stories reduces mysterious illness to a metaphor. Illness is not associated with one particular feeling or one particular response. Each story presents a fullness of feeling and a balance of meanings. Attentive reading yields a variety of responsive choices, including that of care, available to those facing mysterious illnesses. The compassionate response overrides fearful responses.

Stories are powerful vehicles for the understanding and resolution of our culture’s insufficiencies. We will be freed from metaphors, not by denying our insufficient responses, but by understanding that we do have alternate ways of thinking about and responding to patients with AIDS.

Conclusion

AIDS has a powerful emotional effect, and some of our responses to persons with AIDS reveal our insufficiencies. Caregivers experience strong feelings associated with illness—feelings that are often manifestations of fear. Careful reflection about these feelings suggests their association with death, sin, crime, war, and community division. These restricted meanings threaten to classify the person with AIDS as one who is already dead, a sinner, a criminal, an enemy, or an outcast. Yet both reality and fiction remind us that the person with AIDS does not merit evasion, death, punishment, aggression, or neglect. If anything, stories can help caregivers better understand the additional burdens that restrictive meanings for AIDS can impose.

Although each of the metaphors discussed constitutes a way of perceiving and dealing with threatening illness, caregivers need to assess each meaning’s limitations and consequences for treatment. Insufficient metaphors can be recognized as such and then replaced by fuller, more humane images.

Camus’s (1947) more positive images serve as an example. AIDS can help us to reflect about the quality of our patient-therapist relationships. We can let AIDS soften our hearts so that we can be warm and tender with our patients. We can respond with common decency, believing that our collective destiny depends on our response to such a major challenge as AIDS. We can rise above ourselves. We can unite to help the person with AIDS enhance his or her life and, if necessary, face his or her death. As occupational therapists who are often part of the shrinking circle of caregivers for the person with AIDS, we can commit to compassion as we provide appropriate treatment.

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