AIDS: A REVIEW FOR SOCIAL WORKERS

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ABSTRACT

This paper was originally a speech that examined AIDS from the perspective of a social worker practicing in a health care setting. It supports the notion that AIDS patients are most likely to rely on the medical social worker for assistance. Due to the radical media coverage, it appears necessary to address myths associated with AIDS within the context of social work as has been done in other professions such as dentistry and funeral services. This paper tackles the myths as related to social work from four points: 1) A Biological Explanation; 2) Questions Commonly Asked by Social Workers; 3) The Social Functions of Fear; 4) Therapeutic Intervention. It is hoped that social workers can lead other professionals in squelching myths that inhibit quality health care for AIDS patients.
INTRODUCTION

I would like to preface by saying that most of my initial understanding of AIDS/ARC comes from the research under the supervision of Lydia Temoshok and Jane Zich, who are both clinical psychologists with the Langley Porter Institute at the Medical School, University of California in San Francisco. I don't think I have ever been so profoundly impressed with researchers and psychologists.

This discussion will be divided into three parts. The first part will be a simple biological explanation of AIDS. In fact, this explanation is not complicated; however, it is complicated to try to stop the process. Microbiologists are having a terrible time. The second point is the "cycle of fear" and its implications for social work and for social science research. The last issue to be addressed is therapeutic intervention or what social workers can do when face with a client who has been diagnosed with AIDS/ARC. ARC is the diagnostic phase prior to having the AIDS diagnosis.

As a student of sociology, my professors would be profoundly upset with me for giving a biological explanation of AIDS—they would call it "reductionism." I have found, as a social worker, that I come to grips with my clients on a more effective level when I am able to reduce a phenomenon down to the biological level and begin to raise it up to a social-psychological one. I think this explanation has helped me a great deal; therefore, I feel that it is well worth the presentation.
BIOLOGICAL EXPLANATION

The question that many people ask is "what happens to the immune system for someone who has AIDS?" Prior to elaborating on this subject, we need to take a look at the activities of the white blood cells, particularly for healthy persons. In a healthy person, white blood cells circulate through the blood stream and search out and destroy foreign invaders. The white blood cells attack a virus infected cell and render it harmless. There are two important kinds of white blood cells: 1) white blood B-cells; and 2) white blood T-cells. B-cells originate in the bone marrow. There are two kinds of white blood T-cells: 1) T-helper cells; 2) T-suppressor cells. There are many other kinds of white blood cells, but these are the three that are important for the present discussion.

Each micro-organism that invades the body has a unique chemical marker on its surface. Figure 1 ("The Find") illustrates the invader cell and the B-cell. On the surface they are like a lock on a door. The invader cell roams the blood stream causing destruction. When a B-cell comes into action it recognizes the invader and if it has the same chemical marker on its surface, it begins to attack it as illustrated in Figure 2—entitled "The Call." There are many invader cells and as a result the white blood B-cell must send out a chemical alarm to the white blood T-helper cell. The T-helper cell is quite significant because it is the manufacturer of other B-cells (Figure 3, "The Battle") that have the correct chemical combination to destroy the invader cells. The T-helper manufactures cells to destroy the invaders. In figure 4 (entitled "The Victory"), all the invader cells are dead. At this point the third type of white blood cell comes into action--the T-suppressor cell. The T-suppressor cell and the T-helper cell are sisters. The
The Find

Unique chemical markers (lock) → Invader cell → Key that matches the lock of the invader cell.

Figure 1

The Call

Invader cell

Invader cell → White blood B-cell → Call for help!

Figure 2
The Battle

3.

WHITE BLOOD B-CELL

INVADER CELL

STIMULATE PRODUCTION OF B-CELLS TO FIGHT THE INVADERS

Figure 3

The Victory

4.

WHITE BLOOD B-CELL

WHITE BLOOD B-CELL

INFERIOR T-CELL

REPORTS THE DEATH OF THE INVADERS' CELLS AND CALLS OFF THE TROOPS

Figure 4
T-suppressor cell reports the death of the invaders to the cells and calls off the troops. This is an explanation of what happens in the healthy person.

In the healthy person there are twice as many T-helper cells as T-suppressor cells. In the AIDS person, the ratio is exactly opposite. The AIDS person has many suppressor cells that signal the B-cells to disperse. There are fewer T-helper cells that produce the B-cells to fight off the infection. Thus, people do not die of AIDS. They die from what physicians call "opportunistic infections." Patients have no way of fighting off colds or the flu. They have no defense mechanisms against any kind of cancer. Typically, AIDS patients die within 18 months of diagnosis. Yet, these statistics are rapidly changing.

These patients are living longer now. As each month goes by our knowledge of AIDS increases tremendously. In fact, I became frustrated when I first realized that I was making this talk. I began to review the literature and realized that data from last month is too old to report. The two best regular resources for AIDS is Science, and the New England Journal of Medicine. The best literature for any social worker is the work of Langone (1985).
QUESTIONS SOCIAL WORKERS ASK

The first question that most social workers ask is "Where does AIDS come from?" Geographically, epidemiologists suggest that it originated in Zaire. Tragically, all of the surrounding countries of Zaire are seeing AIDS in epidemic proportions.

"What exactly happens to make AIDS proliferate like it has?" The green monkey's natural habitat is Central Africa (Zaire). Some carry a virus called STLV3, \(^1\) which is chemically similar to the AIDS virus (HTLV3). How was this monkey's virus transferred? These monkeys are quite pesty. They have been known to tear up trash cans, and local residents try to scare them away. As a defense the monkeys will attack people by biting. Researchers have suggested that a bite or scratch from a carrier monkey may cause the transfer (Langone, 1985). The green monkey is eaten by the people in Zaire. It is also suggested that the virus has mutated from the STLV3 to the HTLV3. The green monkeys are the only monkeys that the virus does not affect. Chimpanzees and rhesus monkeys are affected just like human beings. Kakni (1985) indicates that the best scientific procedure for tracking down a cure for AIDS will be to study the biological system of the green monkey.

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1. In medical jargon, the virus is written STLV-III but pronounced STLV3. For the AIDS virus, it is written HTLV-III but pronounced HTLV3. Experience has taught me to use Arabic Numerals rather than Roman Numerals. This will help avoid those who are unfamiliar with the jargon to pronounce it correctly.
The second question social workers ask is: "what are my chances of contracting AIDS?" People who are non-homosexual, people who do not use intravenous drugs, and people who are non-hemophiliacs have a greater chance of being struck by lightning than contracting AIDS. If one is using dirty needles, one has a greater chance of getting AIDS. For example, medical facilities in Zaire routinely reuse needles. Friedland (et al, 1986) discusses the life of transmission of the HTLV3 virus in humans. Medical researchers made home visits to AIDS victims and concluded that as long as there is no sexual contact, AIDS is not transferred. Drinking out of the same cup of water does not pass the virus, nor does holding children who have AIDS or touching perspiration.

The third question commonly asked is: "How vigorous is this virus?" HTLV3 is not vigorous. In fact, it's much easier to acquire hepatitis. For example, if an eye dropper full of the hepatitis virus was dropped into a swimming pool, and given time to mix with the water, and a syringe was used to pass it, there would be a very great chance of getting hepatitis. When doing the same thing with the AIDS virus, there is virtually no chance of contracting AIDS. There is only a ten percent chance of the virus surviving in the saliva (Friedland, et al, 1986). Many people have commented about Rock Hudson and Linda Evans kissing. Most pathologists and microbiologists who study AIDS say that there is only a remote possibility of passing on the AIDS virus through the saliva. AIDS is much different when it enters the blood stream. Once it gets into the blood stream, it becomes vigorous and strong. No known drug will kill it. On the other hand, if the virus happens to be on one's hand and the hand is washed with soap and water, the virus dies.

Most people ask "why do we see it in homosexuals and not in heterosexuals?"
When homosexuals are involved in sexual activity, they usually participate in anal sex. The anal opening is quite fragile and vulnerable. It was not designed to take the friction and the capillaries in the rectum rupture easily. The virus, which is in the semen goes directly to the bloodstream. This is the primary reason why we see AIDS more in homosexuals than in heterosexuals (in the United States). In contrast, the tissue surrounding the vagina is rubbery. It was designed to accept the trauma and friction that is associated with intercourse. The vagina is quite robust. In fact most physicians will say that the probability of transferring AIDS by traditional intercourse is lower than transferring it through anal sex. Presently, in the United States, there are 15 men to every one woman. In Zaire the ratio is approximately 50-50. Some speculate that there is more homosexuality in Zaire than the government is willing to admit. Yet, Piot (et al, 1984, p. 65) states, "homosexuality, intravenous drug use, and blood transfusion did not appear to be a risk factor in these patients." One must consider three situations that are unique to Zaire: 1) medical staff routinely reuse needles; 2) the people of Zaire eat the green monkey; and 3) the people of Zaire have physical battles with green monkeys.

"Is there any treatment?" Norman (1986) states that physicians can relieve discomfort, but there is no cure. In fact, Norman speculates that lifetime therapy will be required at the present state of the art. This is likely to change soon (Collaborative DHPG Treatment Group, 1986).

Another frequently asked question is "do people who have the virus always get AIDS?" Marx (1986) points out that the answer is "no." Presently there are five hundred thousand to a million people who have HTLV3 positive. Statistically, five
to twenty percent of those who have the virus contract AIDS.

How did AIDS get from Zaire to the United States? No one knows the answer, but many people speculate that it came from Haiti. During the mid 1970's thousands of people were involved in cultural exchange among French speaking countries. Many Haitians were sent to Zaire and vice versa. Thus, the AIDS virus reaches Haiti. How did the virus emerge into the United States' homosexual community? Haiti has been considered a famous vacation resort for homosexuals. They brought AIDS back to their homes and it proliferated in places like San Francisco and New York.

THE CYCLE OF FEAR

Figure 5 illustrates the societal reaction to AIDS. During the early days (top left corner) when people died of unknown causes, the term AIDS was not coined. No one knew what to do about it. If physicians project an image of fear of a disease, the general public will also project this fear. Such fear emerged to the public, and some medical staffs were refusing to treat AIDS patients. Ethically, most basic hospital policy states if staff members refuse to treat patients, they can be discharged. However, no one was fired during this time period. In England, I had a chance to interview the head master of the Royal College of Nursing. He discussed one of his students. She was the first health care practitioner in the world to acquire AIDS from a patient. She entered the patient's room with medical garb—overprotected (rubber gloves, the mast, the sterile apron, the surgical gear, etc). She took the blood pressure and drew blood, but became
Figure 5
over-confident. She turned her head to chat with one of the colleagues. Instead of inserting the needle into a sheath, it pierced her hand. The AIDS virus she withdrew from the patient went immediately to her bloodstream. Ten days later she developed all the symptoms of AIDS. Two years later she was fine and still practicing as a nurse. This incident demonstrates much about misconceptions. This nurse said, "I wish I hadn't been so overcautious. I felt overconfident—I had all this gear on and I felt over-confident and that's what did it."

Patients have a tendency to feel humiliated when medical staff are over-dressed. People who had AIDS were hiding it and not coming in to see their physicians because of the fear projected from the medical community. In fact, in England, in a magazine called the Scottish Gay, bold letters on the front cover proclaimed "DON'T TAKE THAT TEST." Essentially, it was suggesting that anybody who is identified as having the AIDS virus will be rejected within the social structure, and lose friends, jobs and lovers.

There is a direct relationship between panic among the medical community and public panic. Two articles in the British Journal of Medicine (McKechnie, 1983; Pinching, Wadler & Stedder, 1985) debated the dangers of AIDS. Such articles had a tendency to make the virus proliferate. Potential AIDS victims would not submit to a medical exam and would continue to participate in sexual intercourse which passes the disease. Public panic increased, and followed two different paths. Religious fundamentalist groups maintained a stance or moral condemnation of gays. They protested with signs that read "Gods hates homosexuals." This activity increased public panic. What happens to homosexuals who hear that kind of reaction? They continue to fear rejection, AIDS continues to proliferate, and
there's more public panic. There are two parts to that public panic, one functional and one dysfunctional.

Religious fundamentalism is dysfunctional. The functional aspect is related to increased funding for research. Rock Hudson's case seems to have had a dramatic impact on the increased funding for AIDS research. Dionne Warwick's song called "Friends" is another example of gained public sympathy for increased funding. At this point, we are beginning to see many articles and books written truthfully about AIDS—particularly the misconceptions. Articles tend to be written in specialty journals such as The American Journal of Dentistry.

The next three phases on Figure 5 suggest fewer misconceptions. With fewer misconceptions, it is predicted that AIDS victims will seek treatment more frequently. Associated with an increased treatment is a decrease in the proliferation of AIDS. Nurses and physicians who over-reacted at stage number two now have a tendency to be embarrassed about all the things that they said earlier. AIDS victims are now seeking treatment and they are trying to relieve discomfort. Finally, and the statistics are fairly stable, there seems to be a decrease in the spread of AIDS, which is a hopeful sign. When there are fewer misconceptions, when AIDS victims seek treatment, where there is a decrease in the spread of AIDS, there is less panic. If panic is decreased, there will be less funding because there's less fear.

How can researchers find a cure? The doubling rate for AIDS was nine months—that is, the number of diagnoses doubled every nine months. Statistically, if that rate continues after twelve years, every man, woman and child would have AIDS. However, AIDS seems to have bottomed out quickly to have stabilized. In

- 12 -
fact, it may to be going down. People are less fearful, and are reading articles about misconceptions and how difficult AIDS is to contract. Unfortunately, we are still seeing how children can not go to school because they have been diagnosed as having AIDS. In fact, if we take a close look at the biological explanation of AIDS, it is more dangerous for someone who has AIDS to go to school than it is for the people that around the child. If research funding is decreased, we will begin to have more misconceptions of AIDS, but our misconceptions will be more sophisticated in nature. Because of less fear, the general public will probably be less interested in it.

Pathologists and microbiologists say confidently that they feel that there will be a cure for AIDS. Where will it come from? Although funding emerges out of public panic, the social dynamics of the "competitive nature of academic research" is another factor in the ongoing quest for a cure. This is particularly accurate between the French researchers (i.e., Luc Montagnier from the Pasteur Institute in Paris) and the researchers in the United States (i.e., Robert Gallo from the National Cancer Institute). These researchers have a competitive nature that is almost vicious. One must use one's social work skills at reading non-verbal communication to assess the academic competitiveness while watching these outstanding scholars on television.

We find similar phenomena in social science research. Colleagues at the University of California at San Francisco have devoted much of their time to the study of AIDS. They are rushing their understanding of the psychodynamics of AIDS to scholarly social science journals because of an anticipated cure. The decrease in the cycle of fear and the increased probability of a cure will lower interest in
psychosocial research, interest by the general public, interest by academics and most importantly interest by the publishers of scholarly journals.

THERAPEUTIC INTERVENTION

Levine (1979) suggests that individuals who receive a diagnosis of AIDS/ARC meet the criteria for utilizing group therapy. They share the same "problematic situation" and they are expecting the same final disposition. Group therapy is clearly the preferred modality of psychosocial intervention. The experiences and emotional support gained via group dynamics has no other substitute.

Yet, AIDS and ARC patients are not typical terminally ill clients. They differ from other terminally ill patients in at least five ways: First, they are younger. When social workers are involved with groups associated with terminal illnesses, they expect older patients. Second, unlike cancer, "opportunistic infections" the common denominator for AIDS patient. They have a pronounced fear of gaining a viral infection. Thirdly, there is a general complacency among AIDS patients. This negativeness is associated with being a homosexual. The social structure with its homophobia has built a sense of futility. The fourth is that unlike any other disease, (i. e., cancer, leukemia, spinal cord injuries) AIDS has a definite stigma. Group therapy furnishes a tremendous amount of support among the patients. The fifth point is media involvement. No other kind of medical problem has received as much press coverage as AIDS because of this stigma. It is not merely AIDS that induces physical illness, it is also the accompanying depression. Any depression that may be associated with terminal illness is exacerbated by the
In terms of social dynamics, there is little difference between AIDS groups and non-AIDS groups, but five points can be made. In an AIDS group, the patients will come into a group and contact others who will not condemn, fear or withdraw. This may be the first time that a patient receives empathetic understanding since the diagnosis. The second issue that emerges in group therapy is the sharing of drug information. It is beneficial for all patients to discuss how flim flam artists attempt to take advantage of vulnerable patients. Third, and most obvious, patients find group as significant in terms of moral boosting. Since these patients are profoundly depressed and guilt ridden, group increases their feelings of self esteem. The fourth point is related to social isolation. Upon receiving the AIDS diagnosis, people who were normally outgoing become hermits. Lastly, there is a soap opera element in the community. Group therapy functions at a shield. The network of gossip in the homosexual community diminishes when AIDS patients go into group.

Steinbook, (et al, 1986) completed a series of case studies on homosexual men who had the diagnosis of AIDS. It was discovered that patients who have a diagnosis think about the impact of life sustaining treatment. They desire information about the process of diminishing physical capacities associated with terminal AIDS. They have a positive reaction to talking about, and feel better upon understanding their physical manifestations. Steinbook and his colleagues state that there is no way of predicting the medical and social needs of the patients without first talking to them. Within that same context, although patients needed to talk about their physical decline, they did not want to talk to the physicians about it.
This is quite a significant piece of information to social workers. It demonstrates that there is an important role that the hospital social worker should be playing with AIDS patients—that of an effective mediator between the physician and his AIDS patients.

Closely associated with issues related to physical decline is AIDS’ effects on memory bodily functions (like bladder control). Affected young men have a tendency regress to a borderline psychotic state. Research indicates that when patients realize that they are reaching that point, they much prefer to have close friends make decisions for them rather than family. This phenomenon is probably related to the negative experience that many homosexuals have with their immediate family. They trust the judgment of their lovers and friends more than their families who often reject their alternative lifestyle.

The most significant article for health care social workers on AIDS is written by Miller (1986). He discusses the psychosocial implications of the AIDS diagnosis and makes 8 points. The first concerns personal control. Patients may have feelings of hopelessness and helplessness. Formerly physically strong and independent, they have the hospital as the center of their lives. They will receive a weekly examinations, and may feel like a "guinea pig" because once one has AIDS, researchers will ask, "we've got this new drug, can we try it on you?"

Secondly, their self-esteem suddenly drops. One of the most significant aspects associated with an individual's self-esteem in dealing with AIDS is related to the media. All major television networks have had at least two special programs about the disease. In the print media, Alter (1985) illustrates a photograph of someone holding up a sign stating that "God Hates Homosexuals."
Miller indicates that the most important task for social workers is to be non-judgmental, particularly for a person who has contracted the virus through homosexuality.

Miller (1986) also discusses social implications. Closely associated with the sudden drop of self esteem is social isolation. AIDS victims lose their jobs, they are deserted by their friends. His fourth point concerns occupational disruption—missing work when they find out that they have the disease. Many people have been fired—not just in the United States, but also in England. Merely having the diagnosis of AIDS or even having a positive test places the individual in jeopardy of losing a job or of being prohibited in attending school (as with children). Some will be unable to work on a full-time basis and spend much of their time in a health care facility. It is interesting to note that most nursing homes in the United States will not accept AIDS patients. These patients have few alternatives.

There are emotional implications. Miller utilizes a model similar to Kuper-Ross's (1969) "stages of death." First is a stage of disbelief and shock of the diagnosis. A high state of anxiety exists if they are uncertain about the diagnosis. They are also uncertain about their roommate or lover. They begin to lose their cognitive skills and control of the physical self, which is accompanied by depression and self-blaming.

Miller's next stage is anger which focuses on one's past life-style. It is linked to feelings of guilt about being a homosexual. Finally, Miller discusses obsessions. By obsessions, he means a search for new diagnostic evidence or a participation in fadist treatments. Perhaps "compulsion" is a more appropriate term. True
obsessions involve Miller's sexual implications. He writes that there is an immediate decrease in libido followed by 'conceptual disturbances.' Since sexual activity is of central importance among the homosexual community, there is a homosexual affirmation which AIDS destroys. When an individual loses his role identity as a homosexual (sexual affirmation), he experiences feelings of emptiness and/or feelings of guilt. Such acritical disruption in the gay lifestyle negates all the hard-won battles concerning homosexuality.

Miller discusses the cognitive and neurological implications. These are medically predictable and are associated with anxiety and depression states. There are high levels of distractibility, a tremendous memory impairment, and poor ability to concentrate. In a general state of confusion, patients may not be able to find their way back to their rooms. In terms of behavior, one can see inappropriate responses to crisis, both in the medical and social arenas. Personality disorders emerge. Patients who were once predictable and calm become unpredictable and socially awkward. There are dementia-like states: memory loss, inability to concentrate, loss of orientation. Patients may begin to have speech defects. Their cognitive ability is very unreliable, and there are frequent states of delirium. The hospital social worker must be aware of the sudden physical and cognitive changes in order to deal with psychosocial distress.
SUMMARY

This paper elaborates on three issues most important to medical social workers. The biological explanation is important because it decreases fear for social work practitioners who are most likely to have professional contact with AIDS patients, and increases their understanding of the patient's condition. The second point, "cycle of fear," demonstrates how fear is both function and dysfunctional. It concludes that finding a cure for AIDS will emerge primarily from the "competitive nature of academic research." The discussion concerning therapeutic intervention, states that group therapy is the preferred modality. It seems to be the most effective and efficient mode of intervention for an AIDS patient. Research evidence also indicates that the role of the social worker is that of a mediator between the physician and the AIDS patient.
REFERENCES


