In early 1991, Jane Fowler received a rejection from a health insurance company because of an “abnormality” in her blood. When she inquired as to the source of the problem, Jane was informed that the information was confidential, and that she should seek the counsel of her doctor (Fowler, 1997).

A few hours later, I sat in the office of my family practitioner. She looked troubled as she referred to a fax and reported, “Jane, this company insurance claims your blood tested positive for HIV.” Stunned, devastated, I had a second test 2 days later, anonymously this time.

That test confirmed that Jane was HIV positive.

My family and the few friends I told were shocked. I didn’t fit an HIV/AIDS stereotype. I was at that time a 33-year-old career woman, a journalist for more than 30 years. True, after my divorce in the early 1980s I began dating—men my age, several of whom I had known socially for years. I didn’t consider myself promiscuous; I didn’t frequent singles bars. In those days, I knew little about AIDS, only that a mysterious fatal ailment was affecting the gay community. It didn’t occur to me that I would put myself at risk by engaging in sex with a close friend—an attractive, intelligent, amusing man I had known my entire adult life. Yet that’s what happened to me at the end of 1983.

As Jane’s story reveals, human immunodeficiency virus (HIV), commonly referred to by its late-stage expression: acquired immune deficiency syndrome (AIDS), is not just a disease of children and young adults. It is a condition that affects men and women throughout the life course. Indeed, the Centers for Disease Control and Prevention (1995) reports that more than 10% of cumulative HIV/AIDS cases have been identified in people 50 years of age and older. The “graying” of American society in concert with the life-prolonging effects of new forms of antiviral therapy will undoubtedly contribute to an ever-increasing number of older persons with HIV/AIDS in the future.

BY MARY-ROSE MUELLER, RN, PhD
Jane's experience is also illustrative of another facet of the American HIV/AIDS crisis. Studies have shown that older adults are less likely than younger persons to perceive themselves as being at risk for viral infection (Levy & Albrecht, 1989; Stall & Catania, 1994) and, therefore, are less likely to engage in disease preventive practices.

Empirical evidence points to other disturbing elements of HIV/AIDS and the elderly, elements that are fortunately not part of Jane's experience. Older adults are more likely to be diagnosed later in the course of the disease than younger persons (Gordon & Thompson, 1995; Wallace, Pauw, & Spach, 1993). Moreover, health care professionals are less likely to suspect a diagnosis of HIV/AIDS in asymptomatic and asymptomatic older men and women than they are in younger patients (El-Sadr & Gettler, 1995; Keitz et al., 1996). This lack of general awareness of the problem of HIV/AIDS and older adults has had untoward clinical consequences for those afflicted: They suffer disproportionately higher rates of disease-related morbidity and mortality than those in younger age groups (Ferro & Salit, 1992; Kendig & Adler, 1990; Operskalski et al., 1995).

To understand how and why the risk of acquiring the virus and HIV/AIDS often go unsuspected and unrecognized in people over 50 years of age, it is important to take into account, among other considerations, the ways in which social factors contribute to the situation. Indeed, social scientists and health professionals alike have long realized that the appearance and amelioration by defining and attributing meaning to it (Conrad, 1986). Yet definitions of disease are neither fixed nor static. Rather, ideas about disease change over time and are shaped by a variety of social and cultural forces. For example, diminished memory in the elderly was once considered an expected, albeit unfortunate, aspect of the "normal" course of growing older. However, as a direct outgrowth of the actions of medical research and patient advocacy groups, memory change in older adults is now broadly understood as a "symptom" of the biomedical disorder called Alzheimer's disease (Fox, 1989). In addition, social definitions of disease are grounded in different domains of knowledge. For instance, a disease can be referred to by its biological basis (degenerative, infectious), its social dimension (pediatric, disease of Eastern European Jews), and or its moral status (genetic, sexually transmitted). As such, a disease can be differentially viewed and understood depending on which knowledge domain is accentuated in the most common and widely accepted definitions. Hence, in defining a disease we not only give it meaning (or meanings), we also organize our way (or ways) of thinking about and acting on it.

Since it was first recognized in 1981, HIV/AIDS has been variously defined as a plague, divine retribution, a sex disease, a deadly disorder, and an infectious condition. It has also been defined as a disease of certain social groups, such as gay men, intravenous drug users, hemophiliacs, and immigrants, as well as a disease associated with particular types of behaviors, like certain sexual practices, illicit drug activities, and blood transfusions. In addition, the meanings attributed to HIV/AIDS have changed and evolved over time. During the early years of the epidemic, HIV/AIDS was most closely linked with gay men, and for a time, was referred to as the "gay disease"
More recently, however, it has come to be associated with women, children, and people of color. But because most cases of HIV infection have been identified in people under the age of 50, there has been little public acknowledgment and understanding of HIV/AIDS as a condition that impacts the lives of older adults (Riley, Ory, & Zablotsky, 1989; Noakes, 1996). Indeed, one of the consequences that has emerged from the peculiar ways in which HIV/AIDS has been conceived has been the acceptance of the disease as “someone else’s” problem. As a result, elderly people do not view themselves as being at risk for or in danger of acquiring the condition. Not unexpectedly, even though older adults participate in sexual practices in which contact with the HIV virus can readily occur, they are disinclined to use condoms and or to engage in “safe sex” activities (Stall & Catania, 1994).

Thus, the prevailing ways of defining HIV/AIDS have precluded a comprehensive recognition and acceptance of it as a disease of late middle- and older-aged Americans. In addition, the way the disease has come to be defined and understood have served to influence the public’s reaction to those afflicted. Social definitions of HIV/AIDS have also had an influence on the ways health care services and public health campaigns have been organized and instituted to deal with it.

**Social Response to HIV/AIDS**

Defining HIV/AIDS as a condition of identifiable social groups and social practices has lead to a public embrace of it as “their” disease, not “our” disease. Because people diagnosed with HIV/AIDS and those suspected of having the virus have been stigmatized as “them,” and not “us,” they have been the objects of and have suffered from overt acts of discrimination. Indeed, the social stigmatization of people associated with HIV/AIDS has penetrated virtually every sphere of social life. Children have been expelled from school. Families have been denied housing and, even worse, have had their homes and possessions torched. Consumers have been deprived of essential services, such as life insurance, airplane transport, employment, and police assistance. Patients have been denied emergency and routine medical, nursing, and dental care. One of the most extreme cases of discrimination is exemplified in the repeated efforts of some groups to institute public policies which would compel the isolation of HIV-infected persons from the rest of society.

In some ways, older adults are particularly vulnerable to the social stigma of HIV/AIDS. For example, two of the risk factors associated with the disease, certain sexual activities and intravenous drug use, are regarded as socially deviant behaviors. A prevailing cultural image of late middle- and older-aged adults is that they are not sexually active, let alone that they are intimate with more than one partner at a time or that they are sexually active with partners of the same sex. Another image of older adults is that they do not use hypodermic needles to inject illegal substances into their bodies. These culturally entrenched stereotypes may lead to undesirable consequences. For instance, older adults may resist revealing to others information about facets of their lives, such as their sexual and drug-using practices, because they recognize that those practices are socially unacceptable. Yet it is by engaging in these social practices that older adults come to be at greater risk for coming in contact with and being infected with HIV. Older adults with HIV/AIDS may also fear being reproached and scorned by others and, as a result, may withhold valuable information about their health status to family members, friends, or health care providers. As such, the social stigma of HIV/AIDS may create unnecessary obstacles for older adults as they attempt to obtain needed social and health care services.

The stigma of HIV/AIDS may adversely impact the lives of older adults long after they have disclosed their diagnosis to others. For example,

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**The social stigmatization of people associated with HIV/AIDS has penetrated virtually every sphere of social life.**

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The socially held views of HIV/AIDS as a condition of specific risk groups and risk behaviors has had a profound impact on the orga-
ization and implementation of health care. For example, in the first decade of the epidemic, the definition of HIV/AIDS as a fatal infectious condition provided the impulse for some federal policy makers to allocate funds for biomedical research and public educational campaigns to thwart the spread of viral infection among young adults and children (Mueller, 1994).

Yet it has been just this emphasis on HIV/AIDS as a disorder of young Americans that has led to the development of public health efforts that, in some instances, neglect the needs of older persons. For example, it has long been recognized that HIV/AIDS prevention and education programs have been directed more to the needs and interests of gay men and adolescents than to those of older adults (Riley, Ory, & Zablotsky, 1989; Stall & Catania, 1994). The dearth of age-grated information on risk avoidance and risk reduction has no doubt contributed to the lack of awareness of the virus among older persons, as well as contributed to the growing problem of HIV infection and HIV/AIDS in older men and women.

The conceptualization of HIV/AIDS as a disease of young people has had an impact on the delivery of health care services as well. For example, HIV testing outreach efforts and national seroprevalence studies have primarily focused on younger groups at risk for the virus, such as substance users, sexually active men and women, military personnel, and prisoners (El-Sadr & Gettler, 1995; Keitz et al, 1996). In part because they have been overlooked in HIV testing programs, older adults are often diagnosed later in the course of the disease, in some cases only after they have suffered a life-threatening condition, like an acute episode of Pneumocystis carinii (Keitz et al, 1996). One of the consequences of diagnostic delays in older persons is that their illness is more likely to be managed in technologically sophisti-

cated and expensive hospital wards, instead of the less invasive and less costly environments of ambulatory medicine and home health care.

CONCLUSION

There is a lack of awareness among members of the health care community and the public at large that HIV/AIDS is a condition that afflicts persons of all age groups, including those over the age of 50. Gerontological nurses need to be cognizant of some of the social factors that hinder the recognition of the virus in elderly groups, as well as those that serve to impede the establishment of health and social support services to address the peculiar needs of middle-aged and older persons with HIV and AIDS. By being aware of these factors, gerontological nurses can play an important role in bringing about social and policy changes to help erase the stigma of all persons afflicted with HIV/AIDS. Equally important, they can be better prepared to advocate for changes that will improve the services that directly impact the lives and fortunes of older Americans with HIV/AIDS.

REFERENCES


KEYPOINTS

SOCIAL BARRIERS

1. Older adults are more likely to be diagnosed with HIV/AIDS later in the course of the disease than younger persons.

2. Health care professionals are less likely to suspect a diagnosis of AIDS in symptomatic and asymptomatic older men and women than they are in younger patients.

3. Even though older adults participate in sexual practices in which contact with the HIV virus can readily occur, they are disinclined to use condoms or to engage in "safe sex" activities.

4. A prevailing cultural image of late middle- and older-age adults is that they are not sexually active, are not intimate with more than one partner at a time, and are not sexually active with same sex partners.

5. Gerontological nurses need to be cognizant of social factors that hinder recognition of AIDS in elderly groups, as well as those that impede health and social support services.


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