

3

PSYCHOSOCIAL ASPECTS OF NURSING CARE

While epidemics of life-threatening illness have occurred previously in our society, acquired immunodeficiency syndrome (AIDS) is unique among epidemic disease conditions, according to the Institute of Medicine (IOM) (1988). The IOM's rationale included the fact that persons with the illness remain infectious for life and have a high percentage of fatalities, that a notable portion of the affected population is one of the most productive in our society, young adults, and that difficulty in controlling the disease by traditional public health measures has been compounded because AIDS was first identified in previously stigmatized groups: homosexuals and intravenous (IV) drug users. Thus, response to the disease was confounded by moral judgments and attempts to assign blame (IOM, 1988).

In his keynote address to the Fourth Inter-national Conference on AIDS, in Stockholm, Sweden, on June 12, 1988, Kallings (1988) described the mission of controlling the AIDS pandemic as gigantic, noting that "the characteristics of the virus, its modes of transmission, and the psychosocial consequences to individuals" (p. 207) constituted such complex problems that interna-tional efforts must be generated to meet the crisis. Psychosocial concerns associated with the outbreak relate to the progressive psychological and social strain of experiencing chronic infection and associated illness conditions over time with the potential for death (Redfield & Burke, 1989; Fine-berg, 1989). Mann (1988) reported that while some limits may be set on the human immunodeficiency virus (HIV) because of its limited modes of transmission, "the range, pattern, timing, and extent of transmission depend upon an extraordinary blend of individual behavior, social practices, and possible biological co-factors" (p. 209).



Research related to other chronic illnesses such as cancer and end-stage renal disease has demonstrated associations between psychosocial variables and disease etiology (Mechanic, 1968; Coe, 1970; King, 1972), and may well provide some analogies for HIV infection. Because of the severity and terminal nature of end-stage infection with the HIV and its associated illness syndromes, numerous psychosocial variables act on and interact with the coping response and may have an impact on disease progression. Thus, the psychosocial aspects of HIV infection are of notable concern to nurse researchers. This chapter addresses key psychosocial variables, risk groups, and nursing issues associated with HIV infection. Studies of such factors will provide data on HIV-related patient problems and needs from which appropriate nursing therapeutics may be derived.

State of the Science

The literature contains very little nursing research on the psychosocial aspects of HIV infection. Indeed, due to the relatively recent identification of the disease, minimal longitudinal psychosocial research has been completed by any discipline. Kaplan, Johnson, Bailey & Simon (1987), in presenting a critical review of the AIDS literature and a proposed agenda for future research, identified a number of psychosocial variables as having potential for impact on the course of HIV infection. They reported that the stress related to any chronic illness may be mediated by such factors as social support, locus of control and coping mechanisms. Coping was identified as a variable that may directly influence stress and which in turn affects immune competence (Kaplan et al, 1987). Their suggestions for future research regarding psychosocial response to HIV infection included: identification of a broad range of explanatory variables supported by a theoretical base from which causal models may be derived; inclusion of putative precursors of variables linked to the onset or course of HIV infection; use of designs that provide for the emergence of serendipitous findings; and use of prospective longitudinal methodologies (Kaplan et al, 1987).

Critical Psychosocial Variables

While multiple psychosocial variables might be identified as appropriate for research, selected key concepts highlighted by Kaplan et al. (1987) or studied by nurse researchers in chronic

illness are social support, control, and psychosocial adaptation, including such factors as coping, social isolation and stigma.

Social support. Social support for the HIV-infected individual has been studied and is reported to vary considerably (Flaskerud, 1987). In some cases, homosexual male HIV-infected individuals are afforded the comfort and support of their nuclear families (Ashley, 1986; Moffat, 1987). For others, however, moral or religious beliefs preclude acceptance within the family group (Shelp, Sunderland, & Mansell, 1987). In such cases a partner/lover and a network of friends may provide the primary support (Nungesser, 1987). Infected heterosexual or bisexual men and women sometimes have spouses available for social support (Greenly, 1987), although feelings of anger and/or guilt relative to disease transmission may be experienced by both parties (Kubler-Ross, 1987). Support may also be provided to HIV-infected persons through other sources, such as AIDS peer groups, homosexual family members or partners, Alcoholics Anonymous, or other religious or community groups (Ribble, 1989).

In a study of 50 relatives of persons with AIDS, Frierson, Lippman and Johnson (1987) found notable concerns about transmission of the illness to significant others; and Geis, Fuller, and Ruth (1986), who studied a small group of partners of persons with AIDS, reported that these primary support persons demonstrated a high degree of stress and were themselves often in need of social support. Parents of HIV-infected infants and children require support for themselves as well as for their children. Probably the most neglected group in terms of social support are HIV-infected individuals who are also IV-drug users (Williams, D'Aguila, & Williams, 1987). For all patients, social support may wax and wane over the course of the illness, but family, partners, and/or friends generally rally as the patient's condition becomes terminal (Peabody, 1986). To establish more significant behavioral parameters on which supportive therapeutics may be based, patterns of social support must be further explored within and across risk groups, as well as over time.

Control. Wallston and Wallston (1981) described adaptation to illness as being modified by an individual's perception of whether his/her health was controlled by internal (self) or external (other) factors. The issues of control/loss of control are important for the HIV-infected person whose compromised immune system provides the opportunity for physiological attack by a host of micro-organisms (IOM, 1988). Psychological stressors such as loss of lovers or friends, social stigma, dependence, or fear of death are thought to compound this problem (Altman, 1987; Morin & Batchelor, 1984; Rubinow, 1984). Resultant fear and depression may lead to anticipatory grieving behavior and occasionally terminate in suicide (Marzuk et al, 1988; Saunders & Valente, 1988). Perceived loss of control may also be manifested as a profound sense of powerlessness which is aggravated by external factors during treatment such as lack of or contradictory information about HIV, diagnostic ambiguity, and painful tests and treatments (Langone, 1988). There is a decided need, therefore, to understand the HIV-infected individual's basic perceptions regarding personal versus other control with regard to health and illness issues.

Cohen and Weissman (1985) reported that the more alienated and alone an HIV-infected patient becomes, the more pronounced the physical symptoms appear to the individual. If patients are unable to perceive that their behavior has any impact on the course of their disease, profound depression, anger, loneliness, and hopelessness may result (Rogers, 1988).

Many chronically ill individuals, including those with HIV infection, derive comfort and positive results from the belief that their attitudes toward life in general and/or toward their illness condition in particular may influence the course of the disease and perhaps even the final outcome (Shilts, 1987). Thus, a multiplicity of "alternate" therapeutics are being employed. These include special diets, health foods, herbal remedies, meditation, and relaxation techniques (Martelli, Peltz, & Messina, 1987).

Psychosocial Adaptation. Because of the intense psychosocial stress related to HIV infection, patients frequently have difficulty coping with normal day-to-day activities. Coping with HIV infection is complicated by the fact that the patient may be at risk of "double-stigmatization"; that is, the individual may be perceived as having a dread disease as well as a lifestyle different from what some consider "normal" (Durham & Hatcher, 1984). Namir, Wolcott, Fawzy, & Alumbaugh (1987) reported that simple avoidance coping did not protect HIV-infected patients from distressful feelings and mood disturbances. In a study of the relationship between type of coping and psychosocial outcomes among AIDS patients, these investigators determined that active behavioral coping was positively related to higher self-esteem and was negatively correlated with depression. The findings were substantiated by Nyamathi and Van Servellen (1989), who reported that early identification of ineffective coping is needed to plan for and provide psychosocial interventions to enhance the coping response of HIV-infected persons. Thus, determining effective and efficient coping responses and interventions may facilitate the overall physical and psychosocial adaptation of the infected individual.

Multiple psychosocial stressors confound adaptation and functioning among HIV-infected individuals. For infected homosexuals the diagnosis may involve not only anxiety related to facing a life-threatening illness but also the fear of revealing sexual orientation (Shilts, 1987; Farrell, 1989). This problem has been associated with such psychosocial sequelae as isolation from members of the nuclear family (Fortunato, 1987; Abrams et al, 1986; Egbert, 1988); loss of a partner/lover (Altman, 1987); loss of job or future job opportunities and security (Black, 1986); and the disaffection of former colleagues and friends (Brock, 1988; Lovejoy, 1988). DonLou, Wolcott, Gottlieb, and Landsverk (1985), in a study of homosexual or bisexual male AIDS patients, found a marked decrease in social and sexual relationships after the illness was diagnosed. They suggested, however, that longitudinal studies are needed to fully understand such psychosocial phenomena in this patient group.

A plethora of other psychosocial variables have been identified among HIV-infected patients regardless of sexual orientation or mode of transmission. Salisbury (1986) reported that "the social stigma attached to AIDS has resulted in severe isolation of the patient" (p.14). Anger, both about physical losses related to the illness and the less-than-desired support from partners, has been identified by Feinblum (1986). Such losses were described as particularly difficult for younger persons, in the 20-40 year age group, in whom the incidence of AIDS is highest (Bryant, 1986). Feelings of powerlessness, impotence, and inability to control one's life activities have been reported for HIV-infected persons by Rubinow (1984) who noted also that "sexual activity is lost for some and the sexual act is corrupted as it becomes identified as the mode of transmission of the illness" (p.27).

Finally, a notable psychosocial deficit identified with HIV infection is ineffective coping (Buckingham & Gorp, 1988; Flaskerud, 1989; Langone, 1988; Perry and Markowitz, 1986). Frequently HIV-infected patients are so overcome with the stress of their diagnosis and its concomitant impact on life-style, that previously utilized coping mechanisms are ineffective and illness-related demands exceed individual resources. As coping response indeed influences outcomes (Lazarus, 1966; Lazarus & Folkman, 1984), the identification of effective and positive coping strategies is critical for the patient's overall psychosocial adaptation.

Critical Populations

Intravenous (IV) drug users. Presently, only about 20-25 percent of the IV drug user population is in treatment. As the second largest group of HIV-infected persons, the IV drug user poses a serious threat of transmission to offspring, sexual partners and needle-sharing group members if appropriate precautions are not taken (Galea, Lewis, & Baker, 1988; Newmeyer, 1987).

Identification of potentially successful interventions with this population may be difficult. Faltz and Madover (1988) identified specific psycho-social concerns related to IV substance use and HIV infection that included denial of reality, lack of motivation for treatment and manipulative behavior. Cohen (1987) noted that drug users often are a more hidden group than the other populations at risk for development of AIDS, and that they frequently do not have the benefit of advocacy among themselves or in the larger community. Little research has been conducted with HIV-infected IV drug users because these persons are difficult to locate and/or follow over time, and because they are often unwilling or unable to participate in data collection to assess their needs and problems. However a few successful educational strategies have been reported among the IV drug user community (DesJarlais & Friedman, 1988). Research which provides increased understanding of compliance behavior among this population needs to be greatly expanded.

Women. Women, who constitute a rapidly growing segment of the HIV-infected population, present a great risk of perinatal transmission. Richardson (1987), however, noted that because women still constitute a comparatively small proportion of cases in the U.S., minimal research has been carried out in this group. One exception is the San Francisco-based community study, AWARE (Association for Women's AIDS Research and Education), which is examining women at risk for HIV infection. Women in the AWARE project have identified five major areas of concern regarding HIV infection: 1) transmission (drug use, sexual practices, negotiating sexual encounters); 2) disclosure of antibody status to immediate family, as well as in work or other settings; 3) child bearing and child rearing; 4) access to social and emotional support services; and 5) isolation exacerbated by the small number of women with similar infections (Shaw, 1988).

Children. Infants and children comprise an increasing proportion of the HIV-infected population. According to Oleske, Connor, and Boland (1988), there are between 10,000 and 20,000 symptomatic HIV-infected infants and children in the United States. Such children may be abandoned by family or friends because of the stigma of the illness or because the parents themselves are too ill to provide care. This places a heavy burden on professional caregivers for emotional as well as physical support. Custody issues may arise for abandoned children of HIV-positive mothers. Cultural issues must also be considered because approximately 87% of those who have contracted the disease perinatally are black or hispanic (Department of Health and Human Services, 1988) and many have one or more parents who are IV drug users. Assessment of family resources is critical in the care of the infant or child with AIDS (Boland, 1987). Research regarding effective methods to provide for psychosocial needs of infected children and their parents, caregivers, and siblings is needed.

Professional Caregivers. The need for more information about nurses working with HIV-infected persons has been identified (Flaskerud, 1988a; Flaskerud, 1989; McLeod & Silverthorn, 1988; Van Servellen, Lewis & Leake, 1988), and some research has been conducted (Flaskerud, 1988a; Flaskerud, 1988b; Van Servellen, Lewis, & Leake, 1988). Although it has been suggested that a caring and sensitive staff may be important in helping HIV-positive persons deal with their illness (Chachles, 1986), insensitivity of health care professionals has been reported by AIDS patients (Pickersgill, 1987; Stephens, 1986; Ungvarski, 1988; Van Servellen, Lewis, & Leake, 1988).

Interventions

Studies of persons experiencing other chronic and progressive diseases may be applicable to research on interventions for the psychosocial problems of those living with HIV infection. For example, Cotanch and Strom (1987) reported that progressive muscle relaxation and imagery alleviated physical and psychological symptoms such as nausea and general anxiety. In a randomized clinical trial, McCorkle and colleagues (1989) found that home nursing care

provided by oncology clinical nurse specialists allowed cancer patients to remain more functional and less symptomatic six weeks longer than patients who did not have home care.

In addition, it has been documented that family members experienced significant psychological burden when caring for loved ones over extended periods of time (Stetz, 1987; Northouse, 1984). Interventions with survivors can make a difference both in survivor adaptation and medical outcomes. Donaldson, McCorkle, Benoliel, Georgiadou, and Moinpour (in press) also reported that home nursing care provided to cancer patients during terminal illness benefited the spouse's health after the patient's death. Others have found that when selected subgroups of survivors received counseling, their drug use, physician visits, and somatic complaints declined (Vachon, 1983; Parkes, 1980; Raphael, 1977). Many of these well established approaches warrant testing with persons with HIV infection and their partners.

Research Needs and Opportunities

While a significant amount of anecdotal literature has identified and described psychosocial variables related to HIV infection, and case studies have described the effect of specific nursing interventions, nursing research in these areas is minimal. Studies are needed specifically in such areas as: examination of psychosocial adaptation over the course of the illness (longitudinal designs); identification and description of social support systems for the ill person and their relationship to coping response; examination of patients' control attitudes and behaviors in dealing with their diagnosis and course of illness; the identification of disabling psychosocial responses to HIV infection and/or exploration of coping mechanisms to alleviate negative outcomes; testing of nursing interventions to assist HIV-infected persons, their partners and families cope with the illness continuum; the examination of the impact of caregivers' attitudes about possibly stigmatizing attributes of HIV infection on their professional practices; the patterns of psychosocial coping and support system for IV drug users afflicted with AIDS; description of psychosocial aspects of illness patterns among HIV-infected women; and nursing research related to the provision of care for HIV-infected infants and children and their families.

Clinical nursing therapeutics proposed in the literature need to be tested through the use of appropriate research protocols to develop plans of care based upon sound scientific principles. Finally, attention should be paid by nurse researchers to the more recently emerging HIV-risk populations, including IV drug users, women, and children. While this chapter has focused on a selected number of psychosocial concepts as examples, nurse researchers should be creative in extrapolating findings from research in other behavioral sciences, which might suggest variables relevant to understanding the nursing needs of the HIV-infected person. Psychosocial variables such as social support, control, and adaptation need to be examined longitudinally to assess changes in psychosocial function, as disease progresses from early to advanced stages.

Recommendations

Based on the foregoing assessment of research needs and opportunities in "Psychosocial Aspects of Nursing Care," the Panel has made the following recommendations concerning research in this area over the next five years.

- Identify psychosocial variables that have a significant impact upon the course of HIV infection, as experienced by different patient populations.
- Examine the relationship of psychosocial variables such as social support to patient and family adaptation to HIV infection.
- Examine variations in psychosocial needs among critical populations such as infected IV drug users, women, and children, and among caregivers of infected individuals.
- Test nursing interventions to promote psychosocial adaptation to HIV infection for both

the patient and his/her significant others.

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TABLE OF CONTENTS

CHAPTER 4