

1990

## Psycho-social needs of patients with AIDS

Nancy Baker  
*University of Northern Iowa*

*Let us know how access to this document benefits you*

Copyright ©1990 Nancy Baker

Follow this and additional works at: <https://scholarworks.uni.edu/grp>



Part of the [Education Commons](#)

---

### Recommended Citation

Baker, Nancy, "Psycho-social needs of patients with AIDS" (1990). *Graduate Research Papers*. 2009.  
<https://scholarworks.uni.edu/grp/2009>

This Open Access Graduate Research Paper is brought to you for free and open access by the Student Work at UNI ScholarWorks. It has been accepted for inclusion in Graduate Research Papers by an authorized administrator of UNI ScholarWorks. For more information, please contact [scholarworks@uni.edu](mailto:scholarworks@uni.edu).

---

## Psycho-social needs of patients with AIDS

### Abstract

AIDS stands for Acquired Immunodeficiency Syndrome and is a disease caused by the Human Immunodeficiency Virus (HIV). The AIDS virus (HIV) may live in the human body for years and can be spread to others before any symptoms appear through sexual contact, use of contaminated IV drug needles and, rarely; through blood transfusions. Also, a woman who is infected with the AIDS virus can give it to her infant either before, during, or after birth. It primarily affects the body by attacking the immune system and leaving the body vulnerable to illnesses that can be fatal. These illnesses are called opportunistic infections and diseases because they seize the opportunity presented by the damaged immune system to move into the body. AIDS cannot be cured. Today about 1 to 1.5 million people in the United States are infected with HIV (American Red Cross, 1988).

**PSYCHO-SOCIAL NEEDS OF PATIENTS WITH AIDS**

---

**A Research Paper**

**Presented to**

**The Department of Educational Administration**

**and Counseling**

**University of Northern Iowa**

---

**In Partial Fulfillment**

**of the Requirements for the Degree**

**Master of Arts**

---

**by**

**Nancy Baker**

**December 1990**

This research paper by: Nancy Baker

Entitled: PSYCHO-SOCIAL NEEDS OF PATIENTS WITH AIDS

has been approved as meeting the research paper requirement  
for the Degree of Master of Arts.

Nov. 7, 1990  
Date Approved

Bob Lembke  
\_\_\_\_\_  
Adviser

11-7-1990  
Date Approved

Richard Strub  
\_\_\_\_\_  
Second Reader of Research Paper

11/8/90  
Date Received

Dale R. Jackson  
\_\_\_\_\_  
Head, Department of Educational  
Administration and Counseling

AIDS stands for Acquired Immunodeficiency Syndrome and is a disease caused by the Human Immunodeficiency Virus (HIV). The AIDS virus (HIV) may live in the human body for years and can be spread to others before any symptoms appear through sexual contact, use of contaminated IV drug needles and, rarely, through blood transfusions. Also, a woman who is infected with the AIDS virus can give it to her infant either before, during, or after birth. It primarily affects the body by attacking the immune system and leaving the body vulnerable to illnesses that can be fatal. These illnesses are called opportunistic infections and diseases because they seize the opportunity presented by the damaged immune system to move into the body. AIDS cannot be cured. Today about 1 to 1.5 million people in the United States are infected with HIV (American Red Cross, 1988).

The AIDS epidemic affects most people in one way or another. Many people are frightened and confused by news and information about AIDS in media reports. Taxpayers are providing monies for research, study and treatment of AIDS while doctors, nurses, clergy, home care health workers, social workers, therapists and many other professionals are working to reduce and relieve the distress accompanying this disease. The lives of thousands of parents, siblings, friends,

lovers, spouses and children are interrupted and changed by the illness and death of a Person With AIDS (Carter, 1989).

The argument could be made that AIDS is not unlike other dreaded diseases such as polio, which at one time medical science could not treat, or some types of cancer which do not respond to traditional or experimental treatment. However, AIDS differs from other diseases, in that it is usually acquired sexually or through drug use; thus it "strikes heavily among people who have already been stigmatized by our society" (Nichols & Ostrow, 1984, p. 130). The vast majority of all AIDS cases reported in this country since 1981 have been in people who are homosexual and/or IV drug users (American Red Cross, 1988). Tiblier, Walker and Rolland (1989) add that AIDS patients tend to be young and "thus death is out of phase with the expected life cycle" (p. 113). Nichols and Ostrow (1984) stated that "more than any other population of cancer patients, this one suffers a dramatic change in self-esteem, daily habits and general lifestyle in response to the disease" (p. 72).

Forstein (1984) contended that the greater psychosocial impact for those with AIDS can only be understood by considering the multiple presenting problems of a minority in our society. Persons with AIDS experience social reactions that affect their self-esteem and encourage feelings of

"alienation and isolation." The disease causes changes in body image and the patients lose control over their own lives.

Because most persons with AIDS are already branded by our society many of them do not have family, church and community support networks that usually support the patient in their psychological reactions to dying (Nichols & Ostrow, 1984). Kelly and Laurence (1988) added that the psychological, social and support needs of patients with AIDS are not only "more pronounced" but "less easily addressed." The patients with AIDS have fewer resources available to them, and professionals assisting them are often not trained to deal with the problems of patients with AIDS.

Tiblier, Walker and Rolland (1989) provided us an example of a key issue new to therapists. For many patients with AIDS, the diagnosis forced the revealing of a lifestyle unacceptable to the family of origin at the same time as disclosure of the fatal illness. From this may come further stress due to "conflicts of loyalty" for the patient, such as between the family of origin and the lover.

The object of this research was to evaluate the amount of time persons with AIDS required from the psychosocial staff at Cedar Valley Hospice of Waterloo, Iowa. The purpose of this paper is to detail that investigation and relate the results to the hypothesis reflected in the literature, that

Persons With AIDS require greater psychosocial time, due to greater psychosocial needs than matched peers with other terminal diseases.

#### Method

Data was obtained from 47 deceased patients' charts at Cedar Valley Hospice, 200 East Ridgeway, Waterloo, Iowa. Data was collected from the charts of all deceased Patients with AIDS and also from charts pulled at random for patients less than fifty years of age with other diseases. Age of patients was controlled to match age range of Patients With AIDS. This was to determine if some issues are common to patients under fifty years of age, or are unique to Patients With AIDS. Data was collected on the following variables: age, sex, quality of support system and number of phone and direct contacts made by the psychosocial staff.

A seven item questionnaire was administered to Cedar Valley Hospice staff. The answers were used to determine whether the nurses, psychosocial team members and other staff perceived working with Patients With AIDS as more stressful and time consuming than working with patients with other diseases in the same age range. The 13 responders were also asked to give their thoughts as to why or why not working with Patients With AIDS was more stressful.

Various statistical analyses were used to accept or reject the hypothesis that Patients With AIDS require greater psychosocial time, due to greater psychosocial needs than peers with other terminal diseases. All statistical analysis was done using the SAS program on the VAX 6000-410 computer at the University of Northern Iowa, Cedar Falls, Iowa.

Each variable was correlated with Patients With AIDS and patients with other diseases using a discriminant analysis. This analysis gave a probability value for each variable. The probability value was used to determine if a variable was significant or not in relation to the disease of the patient. The value required to designate a significant variable was a probability of less than .05.

A stepwise discriminant analysis for each variable was also done. This type of analysis had all the variables entered, and the most significant variables were once again determined by a probability value of less than .05. Any variable with the value of less than .05 was pulled out of the model and analysis of the remaining variables continued until there were no variables left with less than a .05 value.

The questionnaire was analyzed using a cumulative frequency on the responses to reflect a trend. Given the small sample size, a high degree of precision was not intended. The discovery of staff perceptions was of primary concern.

## Results

Only two variables had a probability of less than .05. One was number of psychosocial contacts and the other was social support. It was demonstrated in the analysis that contact time and social support were inversely related, i.e., the less social support available, the greater the number of contacts requested of the psychosocial staff members. Thus this result supported the hypothesis that Patients With AIDS required greater psychosocial time than peers with other terminal diseases.

The results of the analysis of the questionnaire also supported the hypothesis. Seventy percent of the responding staff perceived Patients With AIDS as requiring more time than patients of similar age without AIDS. The psychosocial staff estimated that Patients With AIDS required one and a half to twice as much time. The nursing staff estimated spending fifteen minutes to an hour more per visit with these patients. An interesting aspect of the nursing staff responses were the reasons for giving extra time. They often stayed to talk "beyond the nurse stuff" because Patients With AIDS "not only had more physical demands, due to the roller coaster nature of AIDS, but were unsupported by the general community and emotionally devastated." One nurse stated, "because every case is so different with so many complications that

are so unpredictable, fear of the unknown is always more frightening for these patients." These responses by Cedar Valley Hospice nurses were supported by Schofferman (1988) who reported that "psychosocial issues are so complex that they often dominate the clinical picture of the person dying of AIDS" (p. 445). A psychosocial staff member said more time was required "due to less support and more unresolved issues and conflicts with gay and/or drug issues." Fifty-four percent reported feeling more stress working with Patients With AIDS due to the same factors requiring the extra time.

#### Discussion

Significance of these results was best established by placing the findings alongside published research findings and sociological studies of AIDS.

As early as 1985, Dilley, Ochitill, Perl and Volberding concluded from psychiatric consultations with AIDS patients that one of the most prominent issues for Patients With AIDS was social isolation. Schofferman reported in Death Studies (1988) that while "psychosocial issues for AIDS patients are similar to those for any dying patient, isolation is more common and often include the biological family of origin" (p. 434). Only one of the eleven Cedar Valley Hospice AIDS patients was without some family support. However, an

important issue to the Cedar Valley Hospice Patients With AIDS was that most had returned to this area to be with family in the last months of their lives. This magnified their social isolation due to the geographical distance from their lovers and friends. Some had bereavement issues due to multiple losses of friends and co-workers to death by AIDS. Some were without health insurance and had inadequate financial resources. Some had been bright, active and productive people. All of them lost control of nearly every aspect of their lives.

Most of the families of Patients With AIDS were not dealing only with the shock of having a family member with AIDS and the knowledge that this family member lived a socially unacceptable lifestyle, but also with being the only support available to the Patient With AIDS. Some of these families required assistance to deal with the multitude of uncertainties about the Patient With AIDS and about the disease. Support for the families needing help comes from Tiblier, Walker and Rolland (1989) who reported that families frequently needed help

- (a) to adjust to the life-threatening diagnosis;
- (b) to deal with fears of contagion; (c) to accept the sexual orientations of family members; (d) to cope with stigma and discrimination; (e) to manage conflict among family members and significant others; (f) to confront a time-limited push for reconciliation; (g) to prepare for loss and bereavement; (h) to shift family roles; and (i) to provide necessary care and negotiate with external systems. (p. 82)

### Conclusion

This study investigated the number of contacts Cedar Valley Hospice psychosocial staff made to Patients With AIDS and to patients with other diseases based on age, sex and quality of family, church and social support systems. While this was a small and limited research study, the results are supported by Cedar Valley Hospice Quality Assurance Studies and by literature reviewed. Results of Cedar Valley Hospice studies in July 1989 and March 1990 of utilization of services to Patients With AIDS demonstrated that psychosocial services were greater in number and in hours for Patients With AIDS than were true for patients with other diseases. The Quality Assurance Committee suspected that the expressed needs for Patients With AIDS and families were greater, making the time appropriate. The lack of social support available to Cedar Valley Hospice Patients With AIDs emphasized in this study was strongly supported in the literature review, and because Patients With AIDS in this geographical area have returned home to die, the support networks common to patients with other diseases were not available to the Patients With AIDS.

While isolation and lack of support is almost always associated with AIDS, the list of other psychosocial needs of Patients With AIDS includes helplessness, guilt, loss of

control, denial, anger, depression, anxiety, bereavement due to multiple losses, legal, financial, social and medical issues, loss of income, unemployment and housing concerns (Nichols & Ostrow, 1984).

Martin (1988) reported that meeting these complex needs of the Patient With AIDS "is an unprecedented challenge for those providing home hospice care" (p. 465). I believe the results of this small research study on 11 Patients With AIDS cared for by Cedar Valley Hospice supports the validity of this challenge.

## References

- American Red Cross. (1988). Men, sex, and AIDS, Stock No. 329535. U.S. Public Health Service Centers of Disease Control.
- Carter, D. B. (1989). Societal implications of AIDS and HIV infection. AIDS and Families. New York: Haworth Press, Inc.
- Dilley, J. W., Ochitill, H. N., Perl, M., & Volberding, P. A. (1985). Findings in psychiatric consultations with patients with acquired immune deficiency syndrome. American Journal Psychiatry, 142(1), 82-86.
- Forstein, M. (1984). The psychosocial impact of the acquired immunodeficiency syndrome, Seminars in Oncology, 11(1), 77-82.
- Kelly, J. A., & Laurence, J. S. (1988). The aids health crisis, psychological and social interventions. New York: Plenum Press.
- Martin, J. P. (1988). Hospice and home care for persons with AIDS/ARC: Meeting the challenges and ensuring quality. Death Studies, 12(5-6) 463-480.
- Nichols, S. E., Ostrow, D. G. (1984). Psychiatric implications of acquired immune deficiency syndrome. American Psychiatric Press, Inc., Washington, D. C.

Schofferman, J. (1988). Care of the AIDS patient.

Death Studies, 12(5-6) 433-449.

Tiblier, K. B., Walker, G., & Rolland, J. S. (1989).

Therapeutic issues when working with families of persons  
with AIDS. AIDS and families. New York: Haworth Press,  
Inc.