The purpose of this study was to identify nurse caring behaviors desired by patients with acquired immunodeficiency syndrome (AIDS) or human immunodeficiency virus (HIV) seropositive. Forty-six adults with either a diagnosis of AIDS or HIV-seropositive participated in the study. Subjects indicated “treat me as an individual” as the highest scoring item. Themes derived from the data included acceptance, respect, treatment of the person as an individual, and nonjudgmental attitudes of the nurse toward the person with AIDS/HIV.

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ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) is a devastating disease. Ryan (1984) has described the person with AIDS as a “victim,” noting that this term is used because of the “intensity of suffering” that is attributed to the disease (p. 19). The individual who tests positive for human immunodeficiency virus (HIV) faces the manifestations of a fatal disease. This disease also labels and isolates that individual in society. Although the nursing care needs of AIDS/HIV patients are similar to the nursing care needs of other clients, there are additional challenges in the nursing care needs of AIDS/HIV clients. These challenges are related to the transmission of the disease and its manifestations, the social stigma associated with AIDS/HIV, and the vast amount of literature continually generated about the disease. Nurses are faced also with the fear of acquiring the disease at work and transmitting it to their families. The nurse caring for a hospitalized patient who has AIDS/HIV must provide care to a patient who is acutely ill. The patient often has unstable vital signs, has pain, may be confused, requires multiple medications, may be isolated, may be afraid, may have no family or significant others, perspires profusely, is incontinent, may have impaired skin integrity, has to be fed and bathed, and has intravenous fluid therapy. Corless, Halloran, and Belyea (1994) and Holloran, Corless, and Belyea (1994) noted that HIV subjects' nursing dependency needs (nursing diagnosis) were higher than the average for medical-surgical patients in a study of nursing dependency needs of 128 HIV patients and 78,687 total patients hospitalized in a large urban hospital.

The nurse providing nursing care to the patient with AIDS/HIV must be knowledgeable about the disease, possess proficient technical skills, possess critical thinking skills, be a patient advocate, and have the ability to provide nursing care. The nurse must also have an awareness of the physical, social, psychological, and spiritual aspects of human needs.

The purpose of this study was to identify the nurse caring behaviors that are perceived as desirable by persons with AIDS or HIV-seropositive persons. For this study, the term nurse indicates any registered nurse or licensed practical nurse who provides nursing care to persons with AIDS/HIV. For the purposes of this study, a nurse caring behavior is defined as an individual’s (person with AIDS or HIV-seropositive person) perception of the actions, attitudes, or other transactions desired in the nurse-patient relationship.

BACKGROUND

The investigation of AIDS/HIV by nurse researchers is fairly recent. Larson (1988) conducted a review of AIDS-related literature and found no nursing research reported from January 1983 through March 1987. Turner (1990) reviewed nursing literature from March 1987 through November 1988, using studies in which nurses assumed a
Caring Behaviors for Persons with AIDS/HIV

Major role. Larson and Ropka (1991) reviewed published nursing research from May 1987 through June 1990. No studies concerning nurse caring behaviors as perceived by AIDS/HIV patients were reported by Turner (1990) or Larson and Ropka (1991). There has been a slow increase in published nursing research that has investigated AIDS/HIV from the patient’s perspective. However, no studies in the nursing literature that explored desired nurse caring behaviors by persons with AIDS/HIV were identified.

There are examples of recent nursing research efforts that focused on the patient’s perspective. O’Brien and Pheifer (1993) evaluated, from the patient’s perspective, the manifestations of AIDS to determine physical and psychosocial needs of persons with AIDS. Van Servellen, Lewis, and Leake (1990) used the patient’s perspective to identify stressors of persons with AIDS on both integrated hospital units and hospital special care units. Patient perspectives also were used by Dancy (1994) in a study in which African American men were asked to identify the needs of AIDS clients and what constitutes an ideal AIDS program. Williams (1991) obtained information from the patient’s perspective in an effort to focus on educational needs of women at risk for AIDS/HIV from their injection drug use or their heterosexual injection drug user partners.

Authors have given personal accounts of providing nursing care to persons with AIDS and the problems that they have encountered in receiving nursing care as well as health care. Examples of care ranged from nurses not feeding, bathing, or providing for other basic human needs, to examples of nurses who were compassionate and provided excellent nursing care (Hamilton, 1988; Mallory, 1988; Peabody, 1986).

Some researchers have focused on positive and negative experiences in the nurse-patient relationship. In a qualitative study of psychosocial responses of persons with HIV, Gaskins and Brown (1992) interviewed 10 subjects with AIDS/HIV who had both negative and positive experiences with health workers. Negative experiences included lack of interest, inadequate care, rejection, problems with receiving medications, and health care workers’ fears about acquiring the disease.

Foley and Fahs (1994) explored hospital care grievances and psychosocial needs that were expressed by persons with AIDS/HIV during interviews with 50 hospitalized AIDS/HIV patients. Patients were concerned about how they were treated by staff. Themes that were derived from the data focused on the lack of communication with the patient related to treatment procedures, admission and discharge procedures, information related to the person’s health, and nursing and medical treatments.

Meeks-Festa, Uhle, Munias, Gerszten, and Creger (1994) studied the satisfaction of 20 persons with AIDS with nursing services provided at an infectious disease clinic. Meeks-Festa et al. developed a questionnaire and an interview schedule with questions related to communication of information about the disease and how the nurse treated the patient. Areas for improvement in services were related to the need for more communication of information about medications and treatment procedures. Nursing services received positive ratings related to helpfulness, availability, patience, and respect. The importance of communication in the nurse-patient relationship with persons with AIDS was supported by this study.

Methods

Design

A descriptive research design was used to identify nurse caring behaviors desired by patients with AIDS or HIV from the subjects’ perspectives.

Population and Sample

The population for this study consisted of persons who had been diagnosed as having AIDS or HIV-seropositive in the southeastern United States. The sample for this study included persons with a diagnosis of AIDS/HIV who agreed to participate in the study and met specific criteria for the sample’s subjects.

Current efforts to control health care costs by decreasing the length of stay in hospitals and treatment in outpatient areas allowed this study to focus primarily on persons with AIDS/HIV in the outpatient setting. Anderson (1989) and Ross (1989) have indicated that because of the high cost of health care, the HIV-seropositive and AIDS patients are treated as outpatients to reduce health care costs. Only seriously ill AIDS/HIV-seropositive patients were expected to be hospitalized during the study. Criteria for the sample of subjects with AIDS/HIV for this study were as follows. Subjects in the sample were at least 18 years of age.
and had a diagnosis of either AIDS or HIV-seropositive status. Subjects had to be alert and could not be confused to be able to give reliable responses. Swanson, Cronin-Stubbbs, Zeller, Kessler, and Bielaiuskas (1992) reported cognitive impairment in subjects who had asymptomatic HIV infection, early AIDS-related complex, advanced AIDS-related complex, and in the subjects with a diagnosis of AIDS.

Patients who were initially diagnosed as having AIDS or as HIV seropositive during the present hospitalization or clinic visit were not included in the sample. This criterion was included to allow the patient newly diagnosed with AIDS/HIV time to begin to accept the reality of being diagnosed with a fatal disease.

Persons with AIDS/HIV are isolated when they have either infectious diseases or have severe immunosuppression because they are susceptible to infections. Isolated persons with AIDS/HIV were not included in the study to prevent the spread of infection to and from those persons.

Individuals who were unable to read or write for any reason had the tool, letter, and demographic sheet read to them and marked according to their responses by the researcher or a significant other.

Instrumentation

Nurse caring behaviors were evaluated using a demographic sheet in conjunction with a Caring Behaviors Assessment (CBA) tool. An open-ended question was included at the end of the tool to ascertain additional aspects of nursing care needs. The open-ended question was: Is there anything else that nurses could do to make you feel cared for and about? If so, what?

The CBA (Cronin & Harrison, 1988) was developed to assess the desired nurse caring behaviors by patients who had myocardial infarctions. The CBA is written at a sixth-grade reading level and uses a Likert scale from 1 to 5, with 5 being the highest value placed on the nurse caring behavior and 1 the least value placed on the nurse caring behavior by the participant in the study.

The CBA was selected for this study because it considers the multiple aspects of nursing care a patient may receive, including physical, psychological, social, and spiritual considerations. The CBA lists 63 nurse caring behaviors that are congruent with the Carative Factors in Jean Watson’s Theory of Human Care. According to Cronin and Harrison (1988), reliability and validity have been established for the CBA.

Procedure

A letter explaining the study, the CBA tool, a letter to participants, and the demographic sheet were sent to administrators of health care agencies. Hospitals, private and public outpatient clinics, physicians’ practices specializing in infectious diseases, AIDS outreach groups, and AIDS support groups were contacted to obtain access to participants for the study. After access to agency clients was obtained, potential subjects who met the sampling criteria were asked if they would like to participate in the study. Those potential subjects who expressed interest in the study were given a packet containing the CBA tool, a letter describing the study, and a demographic sheet. The packets were distributed to potential subjects using one of two methods: by agency personnel or by the author during visits to outreach agencies, clinics, and hospitals. By completing the CBA tool and the demographic sheet, the subject agreed to participate in the study. Subjects did not indicate their names or addresses on the tools or demographic sheets, thus allowing participants to be anonymous. Tools and demographic sheets were not coded in any way to link them with agencies or subjects.

RESULTS

Forty-six subjects participated in the study from four geographical areas in southeastern United States including both rural and urban settings. Subjects ranged from 18 years of age to 55 years of age, with a mean of 33.7 years. Subjects were primarily white (33), 11 were African American, 1 was Hispanic, and 1 subject did not indicate a race/ethnic group. Thirty-nine subjects were male, one was female, and six did not indicate a gender. The educational level for the subjects in the study ranged from the completion of 9 years of education through 18 years of education, with a mean of 12.9 years. Twelve subjects reported a diagnosis of AIDS, and 34 subjects indicated a diagnosis of HIV seropositive. The length of time of known infection was from 1 week to 10 years. Marital status at the time of the sampling was 27 single, 3 divorced, 3 married, 1 separated, 7 living with a significant
other, and 5 did not indicate a marital status. Sixteen subjects had been previously hospitalized with AIDS/HIV, 29 had not been hospitalized, and 1 subject did not indicate a response. Only 1 hospitalized subject who met the sample subject criteria agreed to participate in the study. Forty-five participants were in outpatient health care agencies including AIDS outreach, private and public clinics, and AIDS support groups.

Given the purpose of the study, the mean scores for each specific item on the CBA were considered. The 11 highest ranking mean scores are listed in Table 1 and the 10 lowest ranking mean scores are listed in Table 2. The item, “Treat me as an individual,” was the most important nurse caring behavior indicated by the AIDS/HIV participants in the study. “Visit me if I move to another hospital unit” was the least important item. The responses to the open-ended question: “Is there anything else that nurses could do or say to make you feel cared for and about? If so, what?” are as follows: “just have patience and care,” “realize that my needs are unique and that I require as much love and support as they can give,” “just never doubt how scared their patient really is and how you would feel if the shoes were on your feet,” and “sometimes you might need to talk about things that seem important at the time.”

### DISCUSSION

Themes derived from the survey items with the highest means include acceptance, respect, treatment of the person as an individual, and nonjudgmental attitudes of the nurse toward the patient. Characteristics of the nurse include that the nurse needs to be knowledgeable, technically proficient, sincere, accessible, and able to perform care in a timely manner. Collectively, the items with the highest mean scores indicate that the person with AIDS/HIV desires to be accepted and cared for as an individual human being.

The highest scoring item in the Cronin and Harrison (1988) study was “know what they are doing.” The lowest scoring item was ranked the same as in the present study of AIDS/HIV subjects: “Visit me when I move to another hospital unit.” Six of the same items were considered as most important by both the AIDS/HIV subjects and the myocardial infarction subjects in the Cronin and Harrison (1988) study (Table 1). Four items were considered as least important by both groups (Table 2).

Themes derived from the AIDS/HIV subjects’

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### Table 1. Eleven Survey Items Having Highest Mean Scores for AIDS/HIV Subjects

<table>
<thead>
<tr>
<th>No. of Item</th>
<th>Nurse Caring Behaviors</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Treat me as an individual</td>
<td>4.98 ± 0.15</td>
<td></td>
</tr>
<tr>
<td>3a</td>
<td>Know what they're doing</td>
<td>4.85 ± 0.42</td>
<td></td>
</tr>
<tr>
<td>53a</td>
<td>Know how to give shots, IVs, etc.</td>
<td>4.84 ± 0.42</td>
<td></td>
</tr>
<tr>
<td>5a</td>
<td>Make me feel someone is there if I need them</td>
<td>4.83 ± 0.38</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Treat me with respect</td>
<td>4.83 ± 0.53</td>
<td></td>
</tr>
<tr>
<td>60a</td>
<td>Know when it's necessary to call the doctor</td>
<td>4.76 ± 0.53</td>
<td></td>
</tr>
<tr>
<td>54a</td>
<td>Know how to handle equipment (for example, monitors)</td>
<td>4.73 ± 0.58</td>
<td></td>
</tr>
<tr>
<td>27a</td>
<td>Do what they say they will do</td>
<td>4.72 ± 0.58</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Accept me the way I am</td>
<td>4.69 ± 0.79</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Accept my feelings without judging them</td>
<td>4.69 ± 0.56</td>
<td></td>
</tr>
<tr>
<td>55</td>
<td>Give my treatments and medications on time</td>
<td>4.69 ± 0.82</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: AIDS, acquired immunodeficiency syndrome; HIV, human immunodeficiency virus; SD, standard deviation.

*Most important nurse care behaviors in the study by Cronin and Harrison (1988).

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### Table 2. Ten Survey Items Having Lowest Mean Scores for AIDS/HIV Subjects

<table>
<thead>
<tr>
<th>No. of Item</th>
<th>Nurse Caring Behaviors</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td>Come into my room just to check on me</td>
<td>4.22 ± 0.89</td>
<td></td>
</tr>
<tr>
<td>39</td>
<td>Help me plan for my discharge from the hospital</td>
<td>4.22 ± 1.15</td>
<td></td>
</tr>
<tr>
<td>42</td>
<td>Offer things to make me more comfortable</td>
<td>4.15 ± 1.01</td>
<td></td>
</tr>
<tr>
<td>57</td>
<td>Let my family visit as much as possible</td>
<td>4.13 ± 1.34</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Praise my efforts</td>
<td>4.11 ± 1.04</td>
<td></td>
</tr>
<tr>
<td>21a</td>
<td>Ask me what I like to be called</td>
<td>4.09 ± 0.91</td>
<td></td>
</tr>
<tr>
<td>26a</td>
<td>Touch me when I need it for comfort</td>
<td>4.00 ± 1.25</td>
<td></td>
</tr>
<tr>
<td>49</td>
<td>Consider my spiritual needs</td>
<td>3.98 ± 1.12</td>
<td></td>
</tr>
<tr>
<td>20a</td>
<td>Talk to me about my life outside the hospital</td>
<td>3.93 ± 1.22</td>
<td></td>
</tr>
<tr>
<td>25a</td>
<td>Visit me if I move to another hospital unit</td>
<td>3.61 ± 1.16</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: AIDS, acquired immunodeficiency syndrome; HIV, human immunodeficiency virus; SD, standard deviation.

*Least important nurse caring behaviors in the study by Cronin and Harrison (1988).
survey items having the lowest means include spiritual needs, family life and home life outside the hospital, touch and comfort measures, visits to the client in the hospital, name preference of the client, and praise. Many persons with AIDS/HIV have been abandoned by their families, which may account for lower scores related to families. Strong views of religious groups during the AIDS epidemic also has caused a barrier between the persons with AIDS and these groups, thus possibly resulting in spiritual needs having a lesser importance for some patients.

Meeks-Festa et al. (1994) indicated that respect was a positive aspect of the nursing care that was provided at an outpatient AIDS clinic and respect of the patient was considered a desired nursing care behavior in this study. Foley and Fahs (1994) indicated that subjects in their study had voiced concern related to medication administration, communication between the patient and the nurse, and how the patient was treated by the staff. These three concerns were found to be desired nurse caring behaviors in the present study.

IMPLICATIONS

With increasing numbers of persons with AIDS/HIV, more patients with manifestations of the disease will be seen by nurses and other health care professionals in both inpatient and outpatient health care agencies. During encounters with health care professionals the persons with AIDS/HIV may not be able to voice desired nursing care behaviors because of mental status or other illnesses. A fear of not receiving the care and treatment needed also may cause the patients with AIDS/HIV not to voice their needs.

Nurses and other health care professionals can use themes from this study to provide care by practicing desired nurse caring behaviors. Nursing care delivered with the anticipation of physical, social, psychological, and spiritual needs would mean delivering nursing care that is appropriate and acceptable to the persons with AIDS/HIV.

Nurses need to provide the client with AIDS/HIV individualized care, be technically competent, knowledgeable about AIDS/HIV, sincere, nonjudgmental, trustworthy, and deliver care in a timely manner. Nurses providing nursing care using these behaviors would expedite the client’s treatment in the health care system thereby reducing health care treatment cost.

During encounters with clients in the therapeutic relationship, nursing care delivered with respect for the individual is expected in the provision of care to any client. Clients with AIDS/HIV are no different; care delivered with respect for the individual person with AIDS/HIV will enhance the nurse–client relationship such that acceptable care is given to the client.

In educational settings, nursing educators of students and practicing nurses can encourage nurses and future nurses to care for persons with AIDS/HIV in a manner that is respectful of human dignity, sincere, and accurate, and promotes advocacy for all ill persons. Educational offerings related to the disease should present the disease, and its manifestations and treatment, and must include aspects of how the persons with AIDS/HIV would like to be treated in the health care delivery process.

More nursing research about AIDS/HIV needs to be done from the subjects’ perspectives. Research related to the lived experience with the disease may unveil aspects of care and treatment that are more appropriate and effective for the prevention of the disease, diagnosis, and treatment.

ACKNOWLEDGMENT

The author thanks Dr. Mary Ann Dell, chairperson of the thesis committee, Dr. Kimberly Robertson, member, and Dr. Jim Sutton, member, for their assistance.

REFERENCES


