Assessing the Impact of HIV Disease

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Key Words: acquired immunodeficiency syndrome • behavioral symptoms

This article presents a definition of HIV disease as a four-stage process. The Sickness Impact Profile (SIP) (Bergner, Bobbitt, Carter, & Gilson, 1981) was used to measure behavioral dysfunction in a sample of 15 persons with Stage 3 or Stage 4 (symptomatic) HIV disease.

The areas of work, leisure, cognitive behavior, and emotional behavior were found to be, on the average, most affected by HIV disease. A diagnosis of AIDS does not affect the severity of dysfunction. Functional deficits that are experienced for longer periods of time affect several behavioral categories on the SIP as well as on the overall SIP score.

Infection with HIV is one of the most serious, life-threatening issues of our time. Many infected persons have subsequently developed AIDS (Koop, 1986). It is unknown whether, in time, all those infected with HIV will contract AIDS. This article examines the functional impact of HIV infection for persons who have received a diagnosis of AIDS as well as for those who are experiencing symptoms of HIV disease without a diagnosis of AIDS.

Literature Review

How does HIV infection become AIDS? There is a popular belief that once a person is infected with HIV, the virus lies dormant in the cells until it becomes activated, at which point the person loses his or her immunity, opportunistic infections invade, and the person contracts AIDS (Gonzales, 1988). The HIV-infected person may experience a lesser cluster of symptoms, however, such as lymphadenopathy, fever, and night sweats, which characterize AIDS-related complex (ARC) (Koop, 1986). The Centers for Disease Control (CDC) issued case definitions for physicians to use to definitively diagnose AIDS (CDC, 1987). HIV can do much damage before a positive diagnosis of AIDS is made, such as contributing to memory loss, muscle weakness, increased susceptibility to various infections, slower healing from infections, the creation of the cluster of symptoms known collectively as ARC, virally caused neurological and psychological symptoms known collectively as AIDS dementia complex (Massie, Tross, Price, Holland, & Redd, 1987), and other manifestations that can functionally impair the infected person (Loveless, 1988).

In the present paper, HIV disease is described as a four-stage process to give a sense of the continuum of the illness. Stage 1 is infection with the virus; Stage 2 is seroconversion, in which antibodies to the virus are produced and are present in the blood, and asymptomatic reduction of immunity; Stage 3 is more severe reduction of immunity, lesser opportunistic infections, and the cluster of symptoms known collectively as ARC; and Stage 4 is more severe opportunistic infections, wasting syndrome, and classic AIDS. Stage 4 ends in death. Functional deficits are found in Stages 3 and 4. This model of HIV disease has been presented by Loveless (1988), adapted from the Institute of Medicine of the National Academy of Science's timeline for AIDS infection.

Some of the signs and symptoms of HIV disease and related opportunistic infections include fatigue, muscle weakness, neuropathy, vision loss, significant weight loss, persistent cough, and diarrhea (Bonck, 1987; CDC, 1987; Denton, 1987b). AIDS dementia complex is characterized by memory loss, impaired concentration, mental slowing, confusion, apathy,
withdrawal, depression, unsteady gait, coordination loss, tremor, dysarthria, bilateral leg weakness, impaired handwriting, and hyperreflexia (Massie et al., 1987; Navia & Price, 1986). Functional deficits of persons with HIV disease may include decreased participation in social activities, chronic absence from work, inability to perform activities of daily living independently, and the need for 12 or more hours of sleep daily (Sedaka & O'Reilly, 1986).

Because most persons with HIV disease in this country have contracted the virus from homosexual or drug-related activities (CDC, 1988), much social stigma is associated with the disease. Many people, including health professionals, disapprove of these activities and have fearful, prejudicial attitudes toward the participants (Douglas, Kalman, & Kalman, 1985; Kelly, St. Lawrence, Smith, Hood, & Cook, 1987). Persons infected with HIV have experienced considerable interpersonal losses, including discrimination in employment, housing, health care, and public assistance and losses of social networks, social contact, and touch. Much of this discrimination is due to prejudice and fear of contagion (Friedland, 1987; Holland & Tross, 1985).

Loss is an important life stressor, and stress plays a major role in immune function. For example, Kiecolt-Glazer et al. (1986) have demonstrated that even relatively minor life stress can cause a significant decrease in T-4 lymphocyte counts. T-4 cells, also known as T-helper cells, coordinate the immune system (Gallo & Wong-Staal, 1985); HIV virus attacks these cells. The many losses experienced by persons with HIV disease, therefore, may lead to stress-related loss of immunity, thus further contributing to the progression of the disease (Livingston, 1988).

**Occupational Therapy's Role**

Occupational therapists, as part of a comprehensive, integrated health care team, can greatly help persons with HIV disease manage their stress and deal with their social, psychological, physical, and cognitive losses (Denton, 1987a; Martin, 1986; Pizzi, 1989; Schindler, 1988; Weinstein & De Neffe, 1990). By the end of 1991, a predicted 270,000 cases of AIDS will exist in the United States (Koop, 1986), a fivefold increase over the 55,000 reported cases in March 1988 (CDC, 1988). Information regarding the functional status of this growing population is needed to plan adequately for the special needs of this group. Recommendations have been made to implement comprehensive inpatient and outpatient health care programs designed to meet the physical, neuropsychiatric, emotional, and social concerns of persons with AIDS (Altman, 1986; Volberding, 1985). Anecdotal evidence shows that these holistic programs "have overcome the sense of isolation and provided the psychosocial support system that exceeds [what is] available for patients located outside such units" (DetHovitz, 1986, p. 217).

Occupational therapists have been treating persons with depression, gait ataxia, confusion, muscle weakness, and many of the other functional deficits associated with HIV disease since long before the current AIDS epidemic. Sarah Herenfielder of the American Occupational Therapy Association stated that "except for some basic infection control procedures, treating persons with AIDS just means practicing good occupational therapy" (personal communication, February 1988). Although the principles of occupational therapy treatment do not change for this specific population, persons with HIV disease have their own configuration of functional deficits, cognitive losses, and psychosocial issues that differ from populations whose needs have historically been addressed by occupational therapy (Pizzi, 1988). Information about particular populations is necessary to plan departmental programs, interface with other health care disciplines, and document for third-party payers why reimbursement for particular treatments is needed. O'Donnell and O'Donnell (1987) demonstrated that an increase in knowledge about AIDS helped reduce health care workers' reported stress, perceived risks, and negative attitudes. Knowledge of many aspects of the lives of persons with HIV disease may also help alleviate fears associated with the treatment of homosexuals and intravenous drug users and may facilitate a higher level of comfort for those working with HIV-infected patients. Early intervention may improve the quality and length of life for those who have been infected (Loveless, 1988; Siegel, 1989). The goal of the present study was to determine HIV-infected persons' perceptions of their functional deficits, in order to help occupational therapists adequately plan treatment for this population and coordinate it with other members of the health care team. An additional goal was to examine the influence of the length of time of functional impairments on behavioral dysfunction.

**Method**

**Research Questions**

Are there significantly different patterns of health-influenced behavioral dysfunction between persons who have a diagnosis of AIDS and those who do not have a diagnosis of AIDS but do have a diagnosis of ARC or those who have not been diagnosed but who experience functional deficits due to HIV disease? Does the length of time elapsed from the onset of functional impairments influence behavioral dysfunction?
The Sickness Impact Profile (SIP) (Bergner, Bobbitt, Carter, & Gilson, 1981), a self-report measure of health-related behavior, was used in this study. Because occupational therapy focuses on achieving the highest levels of independence and functional performance, the SIP was considered a useful tool for quickly assessing the functional status of this population.

The SIP comprises 136 statements that describe specific behavioral dysfunctions. The subjects respond to behavioral statements related to their state of health that they believe describe them on that particular day. The statements are grouped into 12 categories of behavior: work, recreation and pastimes, body care and movement, sleep and rest, eating, home maintenance, mobility, ambulation, alertness behavior, emotional behavior, social interaction, and communication (Bergner et al., 1981). Scores are computed for each category and for the SIP as a whole.

Several studies of the SIP have demonstrated satisfactory test–retest reliability for self- and interviewer administration (Bergner et al., 1981; Pollard, Bobbitt, Bergner, Martin, & Gilson, 1976), interrater reliability (Pollard et al., 1976), and internal consistency (Bergner et al., 1981). Construct, convergent, and discriminative validity have also been established (Bergner et al., 1981).

Subjects and Procedure

Many ethical issues must be addressed when dealing with this sensitive area of research. The following steps have been taken to ensure protection of the subjects, based on the guidelines for research on HIV-infected persons established by the American Psychological Association’s (1985) Committee for the Protection of Human Participants in Research.

First, confidentiality was maintained scrupulously. For subjects who were willing to be followed, any identifying information the researcher possessed, such as names and addresses, has been kept separate from the interview protocols.

Second, recruitment of the subjects occurred through intermediaries, such as physicians, support groups, and peers. Intermediaries were given information packets explaining the nature of the study. The intermediaries gave the packets to persons who they knew fit the study criteria and who were interested in participating. Fifteen subjects were recruited.

The researcher administered the SIP through interviews, which took place in locations chosen by the subjects, to ensure maximal comfort. Demographic information was gathered about each subject’s diagnosis, age, gender, education, economic status, mode of transmission of the virus, and elapsed time from onset of functional limitations to the date of the interview.

Each category of the SIP was scored separately, and an overall score was calculated for each subject. The scores reflect a percentage of total possible points in each category; the total score reflects a percentage of possible points over all items.

Results

Of the 15 subjects recruited, 14 (93%) were men and 1 (7%) was a woman; 14 (93%) were Caucasian and 1 (7%) was Hispanic. The subjects’ ages ranged from 21 to 59 years (M = 37.4 years, SD = 9.03 years). All subjects had at least a 12th-grade education, the highest level of education achieved was a master’s degree. Most of the subjects had some college education but no degree. The subjects’ income levels ranged from under $5,000 per year to $40,000 per year. Most of the subjects had an income level under $5,000 per year.

Homosexual encounters were cited by 11 (67%) of the subjects as the mode of transmission of the virus; 2 (13%) of the subjects reported multiple risks, including homosexual encounters, intravenous drug use, sexual encounters with intravenous drug users, and blood transfusions. Blood products associated with hemophilia accounted for the infection of 1 subject (7%), and 1 subject (7%) reported that the mode of transmission was unknown.

Persons with AIDS accounted for 46% (n = 7) of the sample; those with ARC, 27% (n = 4); and those who had not been diagnosed with either of these conditions but who were experiencing functional difficulties or lesser opportunistic infections associated with HIV disease, 27% (n = 4). The time elapsed from the onset of functional difficulties to the time of the interview ranged from 6 months to 48 months (M = 17.5 months, SD = 12.2 months). Those respondents who had experienced functional difficulties for longer than 12 months comprised 46% of the sample; the other 54% had experienced functional difficulties for 12 months or less. For those whose conditions had been diagnosed as AIDS or ARC (n = 11), the time elapsed since the date of the diagnosis ranged from 5 months to 36 months (M = 12.1 months, SD = 9.35 months). The subjects with conditions diagnosed as AIDS or ARC, therefore, had experienced functional difficulties for an average of 5.4 months before receiving a diagnosis.

Table 1 summarizes the scores for each category on the SIP as well as the total scores for the entire instrument. The areas in which function was most greatly affected were work, recreation and pastimes, alertness behavior, and emotional behavior.

A Mann Whitney U test was used to rank data for the subjects with an AIDS diagnosis (n = 7) and for
Table 1

<table>
<thead>
<tr>
<th>Category</th>
<th>Range</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work</td>
<td>10.19-85.55</td>
<td>62.036</td>
<td>31.89</td>
</tr>
<tr>
<td>Recreation and pastimes</td>
<td>11.30-88.70</td>
<td>48.908</td>
<td>22.79</td>
</tr>
<tr>
<td>Alertness behavior</td>
<td>0.00-83.78</td>
<td>29.489</td>
<td>27.91</td>
</tr>
<tr>
<td>Emotional behavior</td>
<td>0.00-61.13</td>
<td>28.548</td>
<td>22.63</td>
</tr>
<tr>
<td>Sleep and rest</td>
<td>0.00-50.50</td>
<td>25.063</td>
<td>16.66</td>
</tr>
<tr>
<td>Home maintenance</td>
<td>0.00-77.10</td>
<td>20.060</td>
<td>20.03</td>
</tr>
<tr>
<td>Social interaction</td>
<td>0.00-57.38</td>
<td>17.517</td>
<td>15.15</td>
</tr>
<tr>
<td>Mobility</td>
<td>0.00-39.22</td>
<td>12.712</td>
<td>13.27</td>
</tr>
<tr>
<td>Ambulation</td>
<td>0.00-30.76</td>
<td>12.439</td>
<td>9.05</td>
</tr>
<tr>
<td>Communication</td>
<td>0.00-31.59</td>
<td>10.078</td>
<td>11.66</td>
</tr>
<tr>
<td>Eating</td>
<td>0.00-19.57</td>
<td>6.175</td>
<td>5.77</td>
</tr>
<tr>
<td>Body care and movement</td>
<td>0.00-14.55</td>
<td>5.205</td>
<td>4.72</td>
</tr>
<tr>
<td>Overall score</td>
<td>5.00-35.69</td>
<td>18.768</td>
<td>10.31</td>
</tr>
</tbody>
</table>

Note. The categories are listed in order of severity of impact: maximal dysfunction = 100, no dysfunction = 0.

Table 2

<table>
<thead>
<tr>
<th>Category</th>
<th>Elapsed Time</th>
<th>M</th>
<th>Mann Whitney U Test Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recreation and pastimes</td>
<td>≤12 months</td>
<td>4.56</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>&gt;12 months</td>
<td>10.29</td>
<td>10.93</td>
</tr>
<tr>
<td>Alertness behavior</td>
<td>≤12 months</td>
<td>6.00</td>
<td>83.5</td>
</tr>
<tr>
<td></td>
<td>&gt;12 months</td>
<td>10.29</td>
<td>72.0</td>
</tr>
<tr>
<td>Mobility</td>
<td>≤12 months</td>
<td>6.00</td>
<td>12.0</td>
</tr>
<tr>
<td></td>
<td>&gt;12 months</td>
<td>10.29</td>
<td>72.0</td>
</tr>
<tr>
<td>Overall score</td>
<td>≤12 months</td>
<td>5.44</td>
<td>7.5</td>
</tr>
<tr>
<td></td>
<td>&gt;12 months</td>
<td>10.93</td>
<td>76.5</td>
</tr>
</tbody>
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* (Bergner, Bobbitt, Carter, & Gilson, 1981).

Discussion

The results of this study indicate that HIV disease has its greatest impact on work. Although 93% of the subjects had been gainfully employed before the onset of functional deficits, 67% were unemployed at the time of the interview. AIDS dementia complex may have contributed heavily to the high scores of some of the subjects in the alertness behavior category. Twenty-seven percent of the subjects reported experiencing AIDS dementia complex, although none had been given that diagnosis by their primary physician. Only 13% of the subjects reported having no functional deficits in alertness behavior.
Emotional behavior scores for some subjects were high, which is not surprising, because of the fact that this population is dealing with a life-threatening illness. Yet some subjects reported no emotional behavioral dysfunction. Many subjects spoke to the researcher about using HIV disease as a means to transform their lives, that is, to find love, happiness, and satisfaction in ways that they had not explored before the onset of the disease.

Large standard deviations (SD > 20) were found for the scores in the above-mentioned categories and for the home maintenance category. Even for those categories in which mean responses were the highest, the great amount of variability indicates differences in both functional deficits and coping responses among persons with HIV disease. Relatively low mean scores and small standard deviations in the eating and body care and movement categories indicate that the subjects in this study had few medically oriented symptoms that would, for example, require nasogastric feeding or result in impaired bowel and bladder control; nor did they have severe physical limitations that necessitated assistance with movement, dressing, and bathing.

Perhaps persons with HIV disease who also have AIDS do have more functional limitations than those who do not have AIDS, because AIDS is described as the final, most serious stage of the four-stage HIV disease process. Yet an AIDS diagnosis accounted for no significant differences in scores on the SIP for any category or for the total battery. A diagnosis of AIDS simply means that the person has met certain medically oriented diagnostic criteria, such as having had specific opportunistic infections or a combination of other infections and low T-cell counts (CDC, 1987). If a person has survived and healed from opportunistic infections, then he or she may feel quite healthy on any particular day. The results of this study indicate that a person's having AIDS does not automatically indicate a severe loss of functional behavior.

Elapsed time from the onset of functional limitations associated with the disease was related to some of the SIP scores. Perhaps this is due to the cumulative effects of the disease over time: that is, although someone may not necessarily be acutely ill, functional deficits may occur as a result of the wear and tear of surviving the acute illness and of decreasing energy levels over time.

**Study Limitations**

A major limitation of this study was the small sample size. Fewer than 5% of the 300 requests for participants yielded subjects for the study. Those who did respond are perhaps healthier and more accepting of their infection than are many persons in this population. A very sick person may be unlikely to make the effort to contact a stranger to participate in research. It appeared that the subjects interviewed, on the whole, were open to facing their problems and limitations and to allowing a stranger to learn of their identity and disease status. These issues may often be threatening for persons with HIV disease. The responses from this sample, therefore, are likely to be skewed toward physical and mental health rather than to be representative of responses from the general population of persons with Stage 3 and Stage 4 HIV disease.

The sample used in this study is not likely to be representative in terms of mode of transmission, age, and racial and ethnic background of the HIV-infected population. This type of demographic information is available only for persons with a diagnosis of AIDS, even as recently as March 1989 (CDC, 1989). No intravenous drug users without other risk factors (who comprise 17% of the population of persons with AIDS) [CDC, 1989], no children or adolescents, and no Blacks, however, were interviewed despite repeated attempts to recruit subjects from these population subgroups. Such limitations in subject selection may be unavoidable, because ethical recruitment procedures should take precedence over the importance of finding a randomly selected, stratified sample.

Another limitation was the instrument itself. Although the SIP is comprehensive in addressing a wide variety of behavioral dysfunctions and has undergone extensive reliability and validity examination, it still measures behavior by self-report. Cognitive deficits, denial, and distortions in the perception of self and behavior may all contribute to the inaccuracy of self-report measures. This may be particularly true for subjects who reported experiencing AIDS dementia complex. All 15 subjects appeared to understand the questions asked, remembered how they felt throughout the day of the interview, and gave examples of behaviors that were consistent with the items discussed. The data may be distorted, however, if the subjects with cognitive deficits did not report as accurately as the subjects without cognitive deficits.
Suggestions for Further Research

A follow-up study of these individuals with the SIP would permit an analysis of scores between the first and second interviews, to establish changes in function over time. An observational study of behaviors may yield more accurate results than would a self-report. Outcome measures of clinical interventions would be useful.

It would also be interesting to study the specific cognitive, emotional, and behavioral strategies that long-term, healthy survivors of HIV disease use to prolong the length of their lives and also increase its quality. Comparisons could be made between the behaviors of the healthy survivors and the behaviors of others who, after infection, are experiencing higher levels of sickness earlier on.

Conclusion

Not all persons infected with HIV necessarily have AIDS, and it is unknown whether they will eventually contract AIDS. Even when persons do contract AIDS, they may still have relatively low levels of behavioral dysfunction.

The degree of impact that HIV disease had on the study's participants varied greatly. Work, leisure, cognitive behavior, and emotional behavior had the highest mean levels of dysfunction. The diagnosis of AIDS did not make a significant difference in the impact of HIV disease. However, a greater impact was noted for persons who had experienced associated functional deficits for longer periods of time in the areas of leisure, mobility, cognitive behavior, and communication, and for the overall SIP score.

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