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Chou, Fang-Yu,

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SYMPTOMS AND SELF-CARE STRATEGIES IN HIV/AIDS:
APPLICATION OF WEB-BASED SURVEY

by

FANG-YU CHOU, MS, RN
DISSERTATION

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Symptoms and Self-Care Strategies in HIV/AIDS: Application of Web-Based Survey

Fang-Yu Chou

ABSTRACT

BACKGROUND: Efforts to understand the patterns of self-care strategies that are used by people living with HIV/AIDS are imperative in planning effective symptom management. Because the World Wide Web has been increasingly used as a tool for surveying patients' self-reported responses, discussing its use in health care research would help to integrate technology in research. PURPOSES: The purposes of this study are to categorize self-care strategies and self-care information resources, determine predictors of self-care strategies reported by people living with HIV/AIDS, and compare how web-based surveys and interview surveys may generate different results. METHODS: A descriptive, correlational design was used and secondary analysis was applied from a study with both web-based surveys and interview surveys (422 valid surveys). RESULTS: The surveys were completed by 359 participants recruited from a web site and five clinical sites. The results from content analysis revealed eight categories of self-care strategies (n = 776): medications (23.45%), self-comforting (15.21%), complementary treatments (14.69%), daily thoughts/activities (12.89%), changing diet (10.95%), help seeking (9.28%), spiritual care (6.83%), and exercise (6.70%). Four sources of self-care information were identified (n = 526): self (34.41%), health care provider (27.95%), personal network (19.20%), and community (18.44%). The coding schemes of these categories had moderate to high inter-rater reliability. There were significant differences in the proportions of most self-care strategies across different information resources and six most commonly reported symptoms. People who completed the web-based surveys (n =

122) were younger, better educated, and more frequently identified themselves as white. There were also significant differences between web-based and interview subjects in terms of the use of self-care strategies and information resources. Logistic regression analysis demonstrated that race was a significant predictor for medications (OR = .55, 95% CI = .33 - .92), self-comforting (OR = 2.17, 95%CI = 1.24 - 3.79), help seeking (OR = 5.71, 95% CI = 2.57 - 12.70), and spiritual care (OR = 5.09, 95%CI = 1.81 - 14.30). In addition, symptom intensity significantly predicted the use of medications (OR = 1.22, 95% CI = 1.05 - 1.40) and gender significantly predicted the use of spiritual care (OR = 3.76, 95%CI = 1.71 - 8.25). DISCUSSION: Health care professionals should pay attention to these variations in symptom management and incorporate them into the care planning. The cultural differences in the use of self-care strategies should also be considered.

Fangyu Chou

Fang-Yu Chou, MS, RN

William L Holzemer

William L. Holzemer, PhD, RN, FAAN
Chair of Dissertation Committee

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CHAPTER 1 THE STUDY PROBLEM

Introduction

Twenty years after the first report of people infected with Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Disease (AIDS), HIV/AIDS is still widespread and affects nearly thirty-six million people globally. In the United States, although the access and use of highly active antiretroviral therapy (HAART) have significantly reduced the number of deaths from HIV infection, the number of people living with HIV/AIDS has increased as deaths have declined (Center for Disease Control and Prevention, 2001a).

While many people living with HIV/AIDS are experiencing longer lives, the unpredictable course and nature of the disease itself have continued to burden body functions and quality of life of people living with HIV/AIDS (PLWA). Symptoms have been the major problems that PLWA encounter throughout the disease. Some symptoms are directly related to the opportunistic infections and other conditions of HIV disease, while others may stem from treatments for HIV disease and related conditions (Adinolfi, 2000). Most PLWA experienced multiple symptoms with various patterns and levels of severity. For that reason, efforts to reduce these morbidity episodes and discomforts through care management and self-care are imperative throughout the course of the disease.

Statement of the Problem

Due to the effectiveness of current therapies, HIV/AIDS has evolved from an acute illness with a high death rate to a chronic illness with recurrent exacerbation of disease condition. Like other chronic diseases, the nature of HIV/AIDS disease progression has impacts on the physiological and psychological aspects of health. People living with HIV/AIDS encounter many psychological, physiological, and cognitive symptoms, such as pain, diarrhea, fever, and depression. Studies have shown that patients in the stages of symptomatic HIV disease and AIDS can experience on average more than ten different physical and psychological symptoms (Mathews et al., 2000; Reilly, Holzemer, Henry, Slaughter, & Portillo, 1997; Vogl et al., 1999). Besides the symptoms accompanying the disease itself, the current antiretroviral agents have brought another set of symptoms that patients may experience due to the agents' adverse effects (Andrews, 1998). These HIV/AIDS-related symptoms significantly impact a patient's daily life and sense of well-being. Managing multiple symptoms and maintaining optimal quality of life have, therefore, become the major daily tasks for the people with HIV/AIDS (Bedell, 2000; Hench, Anderson, Grady, & Ropka, 1995; Zeller, Swanson, & Cohen, 1993).

When living with HIV/AIDS, effective symptom self-care is crucial for the successful management of the progression of symptoms and the discomfort accompanied by such symptoms (McMahon & Coyne, 1989). Whether patients can engage in self-care actively and appropriately may influence functional status, treatment completion, symptom control, effective collaboration with health care professionals, and quality of life (Dean, 1981). Self-care has been suggested to be the major form of health behavior conducted by chronically ill patients themselves, or assisted by their family in their home and community

(Levin & Idler, 1983). As with most chronic illnesses, much of the necessary care for HIV infection is managed in outpatient and home settings. As a result, people living with HIV need to use a variety of self-initiated activities to deal with the physical symptoms and psychological distress from the disease itself and related complex regimens. Therefore, understanding the self-care strategies and resources that HIV/AIDS patients use to control and manage their symptoms is critical for health care providers to implement effective care and to maintain patients' optimal quality of life.

Purpose of the Study

The first purpose of this study is to describe self-reported HIV/AIDS patients' self-care strategies across all types of symptoms and determine predictors of self-care strategies. The Internet has become a new tool for collecting data in medical research projects and clinical practice. Surveys can be posted on the World Wide Web (WWW) and distributed to subjects. However, the usage of Internet surveys in clinical populations has not been well documented. Therefore, the second purpose of this study is to compare characteristics of self-care strategies in web-based surveys versus interview surveys.

Significance

Self-Care in HIV/AIDS

Self-care has become more important for nowadays HIV/AIDS population because of the changes in its disease characteristics. Since current antiretroviral therapy has significantly improved the life expectancy of people living with HIV/AIDS in the United States and other developed countries, the perspective of HIV disease as an acute terminal illness has shifted toward the view of HIV as a chronic illness (Sowell & Moneyham, 1998). With this change of perspective, by which HIV-infected people are seen as living with HIV instead of dying from AIDS, a correspondingly different spectrum of health care needs should be addressed (Morrison, 1993). Like people with other chronic illnesses, persons living with HIV/AIDS manage their care by shuttling among their homes, communities, hospitals and physician offices. Acute care and hospitalization is not always needed due to the variability of the HIV disease course, which is characterized by an erratic, unpredictable trajectory of sudden, unpredictable crises interspersed with long periods of relative wellness. Therefore, an emphasis on issues for out-of-hospital needs, such as quality of life, health prevention, and health maintenance, is necessary (Sowell & Moneyham, 1998).

Self-care is one of the issues that people living with HIV/AIDS face in the long-term management of the disease. The importance of self-care is depicted in the definition of chronic illness as "a condition not cured by medical intervention and requiring periodic monitoring and supportive care to reduce the degree of illness and to maximize the person's functioning and responsibility for self-care (Donnelly, 1993, p.3)." When management of the HIV/AIDS medical regimens becomes more complex, the level of patients' responsibility for their self-care becomes greater. Thus, discussion of self-care should be reemphasized in health care practice and research.

The change of HIV/AIDS demographic characteristics could also require more emphasis on the study of its self-care. In the past two decades, though first labeled as a "gay disease", HIV disease has been gradually invading vulnerable and diverse populations. For instance, in the United States, fifty-five percent of the cases of AIDS reported as of December 1998 are among African Americans and Hispanics (Center for Disease Control and Prevention, 1998). The number of HIV-infected women has also risen due to more people becoming infected through heterosexual contact and injection drug use (Center for Disease Control and Prevention, 2001a). The cultural and educational characteristics in minority and female populations could complicate the issue of HIV/AIDS self-care. A systematic study in this aspect is needed.

Internet Survey

The Internet has also become a new tool for collecting data in medical research projects and clinical practice. Surveys can be posted on the World Wide Web (WWW) and distributed to subjects. Some studies have used the Internet as a study site for administering surveys: coping with the problems of cancer patients (Fawcett & Buhle, 1995); symptoms and sexual practice in chronic prostatitis patients (Alexander & Trissel, 1996); Medical Outcome Study SF-36 questionnaire in the general population (Bell & Kahn, 1996); and, the SF-36 in ulcerative colitis patients (Soetikno, Mrad, Pao, & Lenert, 1997). The advantages of Internet surveys potentially include unconfined geographic boundaries of research subjects, simplified process of data collection and analysis, and easy distribution of surveys. Additionally, the risk of coerced participation can be avoided since Internet participants voluntarily find and select the surveys. However, several possible limitations may need to be considered in Internet surveys. The nature of the population with Internet access may likely produce selection bias. Although the Internet user population is becoming more diverse, the characteristic of a sample collected through the Internet is still unclear. Another possible risk is that Internet surveys are not invulnerable to malicious data. The researchers have no control on who reports the data. Careful scrutiny of results and validation of submitted information (i.e., rejection of any entry with corrupt data) are needed (Houston & Fiore, 1998). As the Internet becomes a common tool in health care practice and research, the application of its use in HIV/AIDS research should be assessed.

CHAPTER 2 LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Relevant Research

HIV/AIDS Symptoms

HIV disease is a systemic disease that brings multiple physical and psychological symptoms to people living with HIV infection. A list of common HIV/AIDS-related symptoms can comprise of up to 90 different symptoms in the physical health, communication, relationships, perceptions, mobility, and emotions categories (McMahon & Coyne, 1989). Besides the symptoms from the disease itself, complications from opportunistic infections and malignancies can cause problems for patients and providers (McMahon & Coyne, 1989; Van Servellen & Aguirre, 1995). The current highly active antiretroviral therapy (HAART) also introduces symptoms like nausea, gastrointestinal distress, kidney stones, and insomnia; these symptoms significantly affect patients' lives (Erlen & Mellors, 1999).

Several studies were conducted to survey the HIV/AIDS symptom prevalence in different health care settings. Mathews et al. (2000) surveyed a nation-wide sample of 3,072 HIV-infected adults in the United States to estimate the prevalence, bothersomeness, and variation of HIV-related symptoms. The study utilized a checklist consisting of 14 physiological symptoms to record those self-reported symptoms during the preceding six months. Of the 14 symptoms listed, the five most prevalent were fever/night sweats (51.1%), diarrhea (51%), nausea/anorexia (49.8%), dysesthesias (48.9%), and severe headache (39.3%). Fifty percent of the patients had two to seven symptoms. Headache was identified as the most bothersome symptom by most of the patients (67%). This study also indicated that the number and bothersomeness of symptoms were greater in women, injection drug users, and persons with lower education level, lower income, and Medicare enrollees who were followed up at teaching hospitals.

In another study conducted in an ambulatory setting (Vogl et al., 1999), both physical and psychological symptom distress were assessed with the use of the Memorial Symptom Assessment Scale Short Form (MSASSF). MSASSF is a symptom checklist that assesses 32 symptoms during the previous week for the AIDS patients in the study (n = 504). The most prevalent symptoms were reported as worrying (86%), fatigue (85%), sadness (82%), and pain (76%). The mean number of symptoms was 16.7. Unlike the previous study (Mathews et al., 2000), in which physical symptoms were reported as the most prevalent symptoms, the respondents in this study reported a prevalence of psychological distress symptoms. The difference may be due to the different stages of disease in patients in the two study samples. The larger number of psychological symptoms on the MSASSF checklist may also have induced patients to report more of that kind of symptom.

Symptoms were found to be the major problem reported in AIDS patients (n = 90) with pneumocystis carinii pneumonia during their hospital stays (Holzemer, Henry, Reilly, & Portillo, 1995). Most patients reported symptoms such as shortness of breath, fever/chills/night sweats, fatigue/weakness, anxiety, appetite change and nausea/vomiting. The medical records of home care AIDS patients (n = 244) also revealed several physiological and psychological signs and symptoms as major health problems (Hurley & Ungvarski, 1994). Dyspnea (56.6%) and memory deficit (34.4%) were the physical and psychological symptoms with the highest occurrence and frequency. The study findings also suggested that women were more likely to report pain, and men were more likely to report diarrhea.

In another study, the Sign and Symptom Checklist for Persons with HIV Disease (SSC-HIV) was used to measure the intensity of 41 signs and symptoms, and both patients' self-reports and nurses' ratings on symptoms were collected (Reilly et al., 1997). Participants from hospitals, home care agencies, and skilled nursing facilities reported an average of 16 signs and symptoms. Ten symptoms were reported by more than 50% of the patients; these included shortness of breath with activity, shortness of breath at rest, fatigue, cough, weakness, dry mouth, insomnia, lack of appetite, concern over weight loss, and headaches. The study reported poor agreement between patients' and nurses' ratings of HIV-related symptoms. Nurses consistently underestimated the frequency and intensity of signs and symptoms experienced by patients.

Symptoms have been found as the critical component influencing health-related quality of life. For example, a lower level of body pain in HIV/AIDS patients was linked with higher quality of life (Holzemer, Henry, & Reilly, 1998). Studies also show that the amount of HIV-related symptoms and symptom distress is strongly related to psychological distress and poorer quality of life (Linn, Monnig, Cain, & Usoh, 1993; Vogl et al., 1999). Fatigue and average severity of symptoms were found to be significantly associated with functional status and life quality (Cleary et al., 1993).

Symptoms and the psychological distress associated with them may also lead patients to delay or reduce appropriate treatment. Patients' interpretations of the absence and presence of HIV-related physical symptoms were found to influence their willingness to seek medical care (Siegel, Schrimshaw, & Dean, 1999). Symptoms were also found to relate to patients' reported treatment adherence. In a regression analysis (n = 420), HIV-positive patients who had higher symptom scores, especially depression, were less likely to adhere to medication regimens, follow providers' advice, and attend their medical appointments (Holzemer et al., 1999). Symptoms are beginning to be investigated as the factors influencing adherence to HAART. Spire et al. (2000) examined the effect of the number of symptoms on HIV-infected patients' adherence (n = 336). The findings from a regression analysis indicated that people who reported more than four symptoms in the first month after HAART initiation were more likely to be non-adherent in the fourth month after the treatment started.

These studies reveal the complexity of HIV-related symptoms and their profound impact on patients' quality of life and treatment outcome. Therefore, symptom management, which includes the prevention, assessment, and treatment of symptoms and whose goal is to avert or delay a negative outcome through biomedical, professional, and self-care strategies (UCSF Symptom Management Faculty Group, 1994), plays an important role in effective HIV/AIDS care management. Effective symptom management requires the collaboration of health care professional and patient. In the process of symptom management, teaching HIV/AIDS patients how to manage symptoms is part of health care professional's role. It is also the intervention that nurses can provide in the long course of disease progression (Lietzau, 1996). Although patients can obtain symptom management advice from professionals, the actual tasks of daily management (e.g., assessment, evaluation, and alleviation) of those complex and unpredictable symptoms still need to be carried out by themselves, their partners, or their friends (Siegel & Krauss, 1991). Therefore, examining what problems patients may experience in their own self-care at home and in the community is significant for effective symptom management.

Correlates of Self-Care

Self-care is a complex concept, and many factors may influence the process of self-care practice. The factors correlated with patients' motivation for self-care and their ability to do self-care have been studied in sufferers of chronic illnesses. Demographic and socioeconomic factors have been examined to reveal which patients have characteristics that are more likely to enable them to perform self-care. For example, adult cancer patients with lower functional performance status, higher anxiety, less social support, and more education were likely to perform more self-care (Dodd & Dibble, 1993). Age was found to be a moderator in the correlation of self-care with other outcomes (Spitzer, Bar-Tal, & Ziv, 1996). For patients with end-staged renal disease, age and personal traits correlated significantly with their self-care performance and self-care ability (Horsburgh, 1999). In addition, gender was found as another key moderating variable in determining whether socioeconomic, social support, interpersonal functioning and symptoms were related to the likelihood that the elderly would engage in appropriate self-care. It was found that men who had greater amounts of instrumental support and did not report depressed mood were more likely to practice appropriate self-care (Edwardson & Dean, 1999).

There are only a limited number of documented studies that discuss the factors relating to self-care in people with HIV disease. The barriers to self-care in low-income white women living with HIV/AIDS (n = 12) were explored in a study using the grounded theory method (Leenerts, 1998). The barriers to self-care were described as (1) health care provider failure to mobilize resources, (2) health care provider devaluing of women, (3) social devaluing, (4) economic problems, and (5) legal problems. The interaction with health care providers was considered critical in encouraging women to engage in self-care since the health care providers hold knowledge and power to mobilize the needed resources.

In another study, Leenerts and Magilvy (2000) found that fear of illness and lack of preparation were the main concerns of these low-income HIV-positive women in actively engaging in self-care. The process of engaging in self-care for these low-income HIV women was described as focusing self, fitting resources by searching ways to live with HIV infection, feeling emotions to deal with the fears, and finding meaning and creative strategies to face the consequences of the disease.

Awareness of one's own diagnosis was a triggering factor in the changing of self-care activities. The study conducted by Lovejoy, Moran and Paul (1988) in gay/bisexual men with HIV disease indicated that the use of self-care activities increased after the patients knew they were diagnosed with AIDS. The results also showed that the use of recreational drugs and stimulants decreased after the diagnosis. Similar results were reported in a later study in gay/bisexual men with HIV disease (Lovejoy, Paul, Freeman, & Christianson, 1991). The findings showed that 35 out of 81 self-care behaviors were increasingly used once the patients became aware of their HIV seropositive status. Furthermore, the frequent use of self-care behaviors was found to be linked with previous self-care patterns, an AIDS diagnosis, and an external locus of control indicator (e.g., what happens to me is beyond my control). Meanwhile, this study found a weak correlation between symptom distress and self-care.

The factors influencing HIV patients (n = 223) toward healthy or unhealthy changes of self-care behaviors were studied by Valente, Saunders, and Uman (1993). Examples of unhealthy self-care behavior change included increased use of junk food or illicit drugs. The number of physical symptoms that HIV patients experienced was found to be positively associated with depression and the change toward unhealthy self-care behaviors. Patients' avoidance in responding to the impact of HIV disease was also found correlated with changes toward unhealthy self-care behaviors. The finding suggested that psychological distress brought on by symptoms is likely to affect individuals' health behavior changes.

In a recent study, self-care was examined as one of the factors associated with health-related quality of life in women living with HIV (n = 287) (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001). In this study, women were asked whether they practiced five health promoting self-care behaviors (diet, sleep, exercise, stress reduction, and taking vitamins). The results showed that women who practiced more health-promoting self-care behaviors reported better physical and mental health and overall quality of life. This finding suggests the significance of self-care practice in affecting HIV patients' overall health.

Symptoms and Self-Care Strategies

Many symptom management studies have been conducted in specific populations, like oncology patients. There is, however, limited literature on exploring the symptom-related self-care strategies of people with HIV disease in particular. Overall self-care strategies have been reported in several categories in those studies with participants having different stages of HIV/AIDS disease. Allan (1990) and Barroso (1995) used qualitative

approaches; the former which also used a naturalistic approach to interview patients, described self-care activities in HIV seropositive but asymptomatic gay men (n = 11). The self-care activities included diet, exercise, stress reduction, life-style changes, and attitudinal adjustments, and the change in dietary pattern, such as eating a macrobiotic diet or more grains, was the most frequently mentioned self-care activity. Participants also described adopting more positive attitudes toward life as a way to regain control of their lives. Since the study was conducted in a group of asymptomatic patients, self-care activities were performed with the aim of preventing disease and promoting health, and few symptom-related self-care activities were reported. In Barroso's ethnographic study, interviews were conducted with long-term AIDS survivors (1995). Fourteen men and six women who had AIDS for at least three years were interviewed. Self-care activity was defined as a focused set of actions that patients use to take care of themselves and to enhance their mental and physical health. Reported self-care activities included discontinuing negative habits, undertaking health-promoting activities (e.g., changing eating habits), being responsible for one's health, and decreasing stress.

Questionnaires were used to record the self-care strategies in gay/bisexual men with HIV disease (Lovejoy et al., 1988; Lovejoy et al., 1991). The AIDS Beliefs and Behaviors Questionnaire (ABBQ), which lists a variety of preventive self-care behaviors, was used to record retrospective and current information about the frequent use of self-care activities, beliefs, and sexual behaviors (n = 178) (Lovejoy et al., 1988). The study findings indicated that with or without AIDS, most seropositive patients reported that more than one self-care activity was used to "fight off their infection." Besides the self-care behavior listed in the questionnaire, additional self-care strategies were self-reported by most of the participants. They were summarized in five categories as nutrition, hygiene, stress reduction, nontraditional medicine, and surveillance. In the later study, which used an 81-item HIV Self-Care Inventory (Lovejoy et al., 1991), similar categories of self-care strategies were described. They were summarized as stress reduction, cognitive strategies, interpersonal relationships, nutrition intake, symptom surveillance, alternative therapies, and hygiene. Although these self-care strategies were not focused on managing specific symptoms, the categories reported in these questionnaires are helpful to describe what types of strategies that patients would use.

Some studies used HIV positive women as the primary participants. Using the focus group method, (Sowell et al., 1997) described the self-care activities of HIV positive women (n = 27). Subjects were asked to talk about the overall activities they did to deal with the disease and stay well. The categories of self-care activities that were generated from the content analysis included: special dietary and nutrition practices, choosing not to use medically prescribed therapies, spiritual reliance and rituals, staying active, cognitive strategies, self-education and adopting healthy life styles. Anastasio and colleagues (1995) adapted Orem's self-care theory when investigating the burdens related to health-deviation self-care and universal self-care requisites in women with HIV (n = 10). The self-care burden was measured using the Self-Care Burden Scale (SCBS). Among the health-deviation self-care tasks, the subjects reported that obtaining resources, eating a special diet and carrying out home treatments, such as taking medications, were reported as most difficult and burdensome. These self-care tasks were relevant to the subjects' symptoms and treatments. As indicated in the study, many of the subjects had wasting syndrome and required nutritional adjustment for this symptom. Although the results of this study are limited due to the small sample size, the findings help to clarify the difficulties that HIV/AIDS patients may experience in the process of performing self-care. With some of the disadvantaged patients in particular, the lack of resources or the complexity of the symptoms may hinder self-care performance.

Self-care strategies in response to HIV/AIDS symptoms were explored in a variety of categories. Diarrhea is one of the most commonly reported gastrointestinal symptoms in HIV/AIDS patients. In one case-control design study, quality of life and self-care strategies were compared among hospitalized AIDS patients with (n = 20) and without (n = 20) chronic diarrhea (Henry, Holzemer, Weaver, & Stotts, 1999). Most of the patients with diarrhea reported self-care strategies such as taking dietary supplements, vitamins, and medications. The findings also suggested that the number of categories of self-care strategies was significantly associated with general health perception ($r = .48$, $p = .037$). No significant correlation was found, however, between self-care strategies and measures of quality of life.

Holzemer, Henry and Reilly (1998) described patient self-reported pain management strategies in a sample of 83 hospitalized AIDS patients. Patients were asked to report both their self-initiated self-care strategies and the interventions that health care professionals provided to them in pain management. In the category of professional-suggested strategies, 78% were related to pain medications, based on the patient reports. Eighty percent of the patients reported using pain medication as an effective strategy. On the other hand, few activities were reported under the category of self-initiated strategies. Fourteen percent of the respondents reported rest and relaxation activities, while thirteen percent reported physical activity and exercise. Although most of the respondents did not report self-care activities, the results showed that some of the reported self-care pain management activities, such as meditation and lifestyle change, were not described in the strategies provided by health care professionals. This finding suggested that some of self-care strategies that patients used were not directed or learned from the health care providers.

The Internet was used to recruit HIV/AIDS patients into a web-based symptom self-care management strategy survey on the WWW (Holzemer & Bakken, 2000). Self-care strategies specific to common symptoms were then analyzed based on these web-based responses along with those of subjects recruited with the paper and pencil method (n = 422 surveys). The self-care strategies, perceived helpfulness, and sources of information were summarized according to each specific symptom by content analyses. The most frequently reported symptom (n = 73) was anxiety/fear (Kemppainen et al., 2000), for which the most frequently reported self-care behavior (n = 162) was talking to others (25.3%). For the second most frequently reported symptom, diarrhea (n = 70) (Holzemer et al., 2000), the most frequently reported self-care strategy was adjusting diet (29%), and about 73% of the self-care strategies for diarrhea (n = 96) were judged helpful by patients themselves. For the third most frequently reported symptom in this sample, peripheral neuropathy (11.6%) (Nicholas et al., 2000), body therapy (massage, acupuncture) was reported as the most frequently used self-care strategy for peripheral neuropathy (31%). For the fifth most frequently reported symptom, depression (8.1%, n = 34) (Eller et al., 2000), the most reported self-care strategy was using distraction techniques (21%). For the seven percent of the participants who reported having fatigue, the most frequently reported self-care strategy was rest and sleep (27%) (Corless et al., 2000). These studies also reported on the multiple self-care information sources for symptom management. Respondents reported that health care providers were their most often used source of information for treating diarrhea and peripheral neuropathy, but that their own experiences formed their most often used information sources on self-care of fatigue, depression, and anxiety/fear.

Self-Care Information Resources

Mobilizing the resources and information available around oneself to promote health or treat illness are acknowledged to be part of the self-care action process (Levin & Idler, 1983; Orem, 2001). Taking the initiative in searching health information is considered one component of health behavior and as a coping strategy for responding to illness (Lenz, 1984). Effective self-care requires patients to possess appropriate knowledge and skills. In the early self-care literature, many reports showed that most patients had treated their symptoms and consulted lay resources before contacting the doctors (Dean, 1981). In addition to the health information provided by health care providers, many patients obtained information from their friends, families, and media about their disease, treatment, and how to take care of themselves (Williamson & Danaher, 1978).

Within the health care system, health care professionals become the primary providers of medical information to patients. It has been reported that the patient's need to obtain health information is commonly underestimated by health care professionals. Catalan (1994) found that the actual preference of HIV-infected patients to obtain disease-related information was higher than health care providers had assumed or perceived (including doctors, nurses, and social workers). Dissatisfaction with and inadequacy of information they receive from the formal health care structure (from their primary health care providers) give patients the impetus to seek other sources of health information. Seeking information from friends or other resources was suggested to be one of the self-care actions that HIV/AIDS patients use to cope with uncertainty about their disease conditions (Allan, 1990).

The information and resources that HIV/AIDS patients use to manage their self-care were illustrated in some studies. Seeking information about AIDS was described as one of the self-care cognitive strategies in HIV/AIDS patients (Lovejoy et al., 1991). Like other patients with chronic illnesses, patients with HIV/AIDS use multiple sources for obtaining information. Lovejoy et al. (1988; 1992) discussed the needs and sources of information for gay/bisexual with HIV disease. Over half of the participants in these studies expressed the need to have more information about building the health and the immune system, handling the side effects of AIDS/ARC-related medicines, fighting off symptoms (e.g. depression), and reducing stress. Their preferred channels for that information were nurses/doctors, community networks, pamphlets, and other unidentified resources. The results also suggested that the HIV seropositive men without AIDS showed significantly more interest in knowing about symptom management, medication side effects, and counseling/financial services (Lovejoy et al., 1988).

The pattern of information seeking in these subjects was measured by the HIV Information-Seeking Questionnaire (Lovejoy et al., 1992), which includes questions about the number of resources, frequency of consultation, and tangible aid (helpfulness and accuracy of information, stability of consultation and impact on self-care behavior). On average, the participants in this study used 5.8 resources. Traditional information resources, such as friends, physicians, and the media (including professional journals) were the most frequently used. Other resources included religious centers, alternative healing, and social security personnel. About half of the patients viewed the above resources as being helpful (58%) and accurate (62%). In addition, about half of the subjects reported that the acquired information had a moderate effect on their self-care behaviors. The findings suggested among the correlates of information seeking that patients who routinely perform self-care are most likely to seek and benefit from additional self-care information. The weak but positive relationship between quality of life indicators and information seeking variables (frequency and tangible aid) suggested that quality of life could be a predictor or outcome of information seeking.

Moran et al. (1988) studied the need for safe sex information among gay/bisexual men with AIDS or AIDS-related complex (n = 76), and used open-ended questions to record which information resources the participants had used. The study found that the patients considered the provision of safe sex information from health care personnel to be inadequate. About half of the patients reported helpful safe sex information was received from the pamphlets and brochures of community groups. The results also indicated that besides these printed materials from the community and peer pressure also affected patients' motivation to change behaviors.

Powell-Cope (1996) conducted a qualitative study to explore how partners influence how AIDS patients manage their symptoms. It described tasks of symptom management assumed by partners involved with gay/bisexual men with symptomatic HIV/AIDS. Symptoms were managed by trial and error, and searching out information from multiple sources, such as friends, family, healthcare providers, and providers of

alternative forms of care. The findings suggested that the patients' partners adjust their involvement as the disease progressed. When the patients became sicker, the partners became more involved in monitoring signs and symptoms, and in securing proper care. When the patients become even sicker, the partners took on more responsibility for managing symptoms.

Summary

These studies suggested that HIV disease itself is an important factor in changing patients' engagement in self-care behavior. The symptoms that patients experience also affect their coping and self-care behaviors. Multiple resources and psychological adjustment to cope with the disease are necessary for the patients to perform appropriate self-care. Factors related to self-care of other chronic diseases that have been proposed in the literature of other chronic diseases, such as personal characteristics, socioeconomic factors, or social support, were not extensively investigated in HIV/AIDS patients. Since self-care is becoming an important skill of chronic illness patients, these factors should be considered when examining their potential relationships with HIV/AIDS patients' self-care.

Although several studies described a variety of self-care strategies that people living with HIV/AIDS use to manage their illness, little research has systematically documented the self-care strategies for managing symptoms. Most of the studies were conducted prior to the use of HAART and had small sample sizes. The introduction of HAART may have changed HIV/AIDS patients' self-care practices as reported in earlier literature. A systematic description of self-care strategies for HIV/AIDS symptoms is needed.

The literature review also shows that there is a lack of discussion about the factors affecting the performance of certain kinds of self-care strategies. To determine what type of self-care strategy is more popular in a certain patient group (for instance, male versus female HIV/AIDS patients), it would be helpful to target useful self-care education. Although it has been suggested that besides the assistance they acquire from the formal health care structure, patients themselves construct their own health care network (family, partner, or peers) for illness management, few studies have documented what information resources relate to certain kinds of self-care strategy. This review highlights the need for continued research in these areas.

This review reveals that studies on HIV/AIDS self-care have utilized a variety of methods and sampled subjects at different points in the course of their HIV illness. The self-care strategies that patients used for managing illness and symptoms have impacts on their symptom status and quality of life. However, few studies have examined factors contributing to the variation of self-care strategies. This study is thus designed to examine the association among personal characteristics, disease characteristics and self-care strategies.

Conceptual framework

Background of Self-Care

Self-Care in Health Care

The concept of self-care has a long tradition in health care literature. Ferguson (1980) suggested that the activity of self-care has been documented since early western civilization, and that from the western medical point of view, the use of folk medicine, home remedies or alternative (indigenous) medicine are considered early manifestations of self-care. During the nineteenth century, several movements focused attention on self-care. These movements were represented by a number of publications of manuals that taught people how to take care of themselves with home remedies and by groups like the Thompsonians, who advocated the use of roots, herbs, homeopathy, and hydropathy (Steiger & Lipson, 1985).

As for contemporary Western public interest in self-care, Levin (1983) summarized several factors that have contributed to this phenomenon:

(1) Epidemiological factors. The shift in disease patterns from acute to chronic disease made self-care an appropriate strategy.

(2) Personal responsibility for health. The associations of life-style factors with morbidity and mortality increased the focus on personal initiatives to prevent disease and promote health.

(3) New health workers and consumers. The bureaucratization of medication made it possible for persons with less professional training to perform various routine medical tasks, which in turn implied the feasibility of extending the lay medical role.

(4) Alternative therapies. Non-allopathic systems of health care became more accessible and attractive from the standpoint of their compatibility with a wider range of cultural values.

(5) Availability of self-care information and technology. The growing corpus of self-care literature provided a productive, self-protective means of using health professional resources. Medical technology designed for lay use, such as blood pressure monitors and home computers, also provided a new set of resources for self-care development.

(6) Impact of broad social movements. Societal changes through the consumer rights movement, civil rights movement, and women's health movement as well as broad economic changes have altered people's views on professional medical control, so they consider self-care as a means of self-management.

The concept of self-care in health care can be discussed from two approaches: self-care as a basic health behavior, and self-care as a supplement to professional services. Self-care is considered as the natural response to illness. The practice of self-care has been proposed as the primary health behavior involving all systems of health care. As Levin (1976) suggested, both self-care and professional care are part of an integrated practice module. Health care professionals must acknowledge that people's integrity in making health decisions and their ability to perform successfully on their own behalf take precedent over any and all existing professional values of risk reduction and disease cure. Williamson and Danaher (1978) also argued that self-care is the first level of health care and the largest part of the health care system. The early studies suggested that individuals themselves manage most of the symptoms and health problems without seeing health care professionals. People conduct self-treatment or self-medication, based on their experience of illness, when they have discomforts (Levin & Idler, 1983).

Freidson (1970) proposed the term "lay referral system" to describe the important role of lay social networks and self-initiated care in medical behavior outside of the professional care system. He suggested that people seek help through a network of potential consultants, from close family members to selected and distant authoritative lay persons, until they reach the professionals. The concept of lay networks broadens the explanation of the kinds of behaviors and resources that people use to manage their illnesses.

From the professionals' point of view, self-care is an important concept to use when encouraging patients to take control of their own health. Factors such as inadequacy of professional care have prompted professionals to emphasize the importance of self-care in patient education (Dean, 1981). A variety of educational programs and materials have been used to strengthen patient self-care skills and abilities for different clinical situations such as tending wounds after hospital discharge, taking medications, or injecting insulin. Although the idea of patient education and self-care are not the same in terms of their underlying philosophies (Levin, 1978), the inclusion of self-care as a goal of patient education encourages more active patient participation. The impacts of self-care practices have been linked with health services utilization and reduction of medical expenditures as well. Fleming, Giachello, Anderson and Andrade (1984) reported that self-care users visit physicians less often and spend fewer days in the hospital. Self-care activities appear to be substitutes for, rather than supplements or stimuli to, health services utilization.

What is self-care?

Descriptions of self-care practices vary depending on the ways in which self-care knowledge is organized. Gantz (1990) summarized the scope of self-care from six perspectives based on academic disciplines: medicine, nursing, psychology, health education, sociology, and public health. Although the foci and goals of self-care vary from one discipline to the next, several aspects of self-care were suggested to be common across disciplines: (1) self-care is situation and culture specific; (2) it involves the capacity to act and to make choices; (3) it is influenced by knowledge, skills, values, motivation, locus of control, and efficacy; and it focuses on aspects of health care that are perceived to be under individual control.

Woods (1989) categorized types of self-care based on four models of health proposed by Smith (1981): the clinical, role performance, adaptation, and eudaemonistic models. According to this scheme, the characteristics of self-care are differentiated according to each conceptualization of health. The clinical model emphasizes health as the absence of disease, symptoms, or bad feelings as well as the absence of need for medical care; self-care becomes what people do in response to symptoms or illness. The role performance model emphasizes health as the performance of one's socially defined roles or the ability to engage in activities of daily living; self-care in this model includes the use of rehabilitation techniques to facilitate functional independence. The adaptation model defines health as flexible adjustment to the environment, including the ability to cope with stressful events; self-care focuses on self-managed strategies to cope with stressful events like illness. The eudaemonistic model of health emphasizes high-spirited well-being and the ability to actualize the self; self-care in this model emphasizes involvement in health promotion or wellness activities.

The actual definition of self-care varies as much as the descriptions of self-care practices. Self-care was once emphasized as self-initiated actions without professional assistance across health promotion to rehabilitation. Levin et al. (1979; 1983) defined self-care as a process whereby a layperson can function effectively on his own behalf in health promotion, disease prevention and detection, and treatment at the level of the primary health resource in the health care system. He suggested that self-care includes those processes that permit people and families to take initiative and responsibility for functioning effectively to develop and maintain their own health. Self-care activities are undertaken without professional assistance, although individuals are informed by technical knowledge and skills derived from the pool of both professional and lay experience. Orem (2001) defined self-care as "the behavior that exists in concrete life situations directed by persons to self or to the environment to regulate factors that affect their own development and functioning in the interests of life, health, or well-being" (p.490).

By contrast, Dean (1989) argued that the component of health promotion is not under the scope of self-care. She differentiated health promotion from the conception of self-care. Although self-care and health promotion can contribute to wellness, Dean argued that health promotion is a broader concept. Self-care is personal behavior that can influence health, but many other factors also influence health (such as physical and social environment, economic conditions, heredity, or health services). Dean narrowed the definition of self-care to aspects of illness management and considered that self-care and professional care were interrelated components. She defined self-care as that which involves the range of individual health behaviors: health maintenance/life-style, utilization of preventive health services, symptom evaluation, self-treatment, and interaction with the professional sector (Dean, 1981).

Self-care strategies are the activities or procedures that patients conduct to manage their health problems. Researchers have suggested a range of different forms of self-care strategies. In her self-care theory, Orem (2001) proposed that the actions of self-care are based on either internal or external orientation. There are four types of externally oriented self-care actions: (1) knowledge-seeking actions, (2) assistance- and resource-seeking actions, (3) expressive interpersonal actions, and (4) actions to control external factors. The two types of internally oriented self-care actions are: (1) resource-using actions to control internal factors, and (2) actions to control oneself (thoughts, feelings, and orientation). Orem did not clearly explain the meanings of external and internal orientations. Based on the types of actions described, however, external and internal orientations may be interpreted respectively as activities relating to the outside environment and activities inside the person himself/herself. Orem also implied that the term "health-deviation self-care requisites" are actions that are necessary for appropriate health care, such as health monitoring, seeking needed health care, treatment involvement, and living with illness.

Dean (1981) delineated self-care activities that include a range of individual health behaviors like health maintenance/lifestyle, utilization of preventive health services, symptom evaluation, self-treatment, and interaction with the professional sector. People engage in the kind of self-care behaviors or activities that they think will help them realize their maximum health potential. Dean et al. (1986) proposed,

> Self-care involves the range of activities individuals undertake to enhance health, prevent disease, evaluate symptoms and restore health. These activities are undertaken by lay people on their own behalves, either separately or in participation with professionals. Self-care includes decisions to do nothing, self-determined actions to promote health or treat illness, and decisions to seek advice in lay, professional and alternative care networks, as well as evaluation of and decisions regarding action based on that advice (p. 62).

In her model of self-care in chronic illness, Connelly (1987) suggested four categories of self-care behaviors: (1) general health behaviors or following health-promotion practice, (2) identifying signs of health problems, (3) seeking consultation and advice for health problems, and (4) implementing specific therapeutic self-care behaviors as recommended. Steiger and Lipson (1985), however, divided the major components of self-care behaviors as: (1) Health promotion, (2) Health maintenance, (3) Disease prevention, (4) Disease detection, and (5) Disease management.

Barofsky (1978) suggested a typology of various forms of self-care behaviors from aspects of therapeutic alliance between patients and providers. Barofsky proposed self-care as a measure of people's socialization into the health care system, reflecting the adaptation of self-care capacity to a specific therapeutic regimen. In short, self-care is a form of self-control and a primary outcome and measure of any health care process. Self-care behavior is thus classified as: (1) regulatory self-care--routine health maintenance activities such as eating, sleeping and personal hygiene; (2) preventive self-care--adherence to self-selected practices such as exercise, dieting or self-examination; (3) reactive self-care--self-initiated responses to symptoms; and (4) restorative self-care--compliance with a professionally prescribed treatment regimen of medication and behavioral change.

In sum, a review of the conception of self-care indicates wide variations as to its scope and how it relates to the concept of health across different perspectives. Disagreements are apparent in whether the use of professional health care services can be included within the domain of self-care and whether health promotion is a part of self-care behavior. One's choice of what concept of self-care to use depends upon the research question being asked and which population is being studied.

Frameworks

Two frameworks are used to guide this study: (1) Orem's self-care model—to understand the fundamental background and attributes of self-care, and (2) Outcomes model—to help identify possible factors related to self-care strategy.

Orem's Self-Care Model

Orem's self-care model has been utilized in a variety of situations in clinical settings and nursing research. It was developed from a nursing perspective and focuses on helping patients learn self-care skills to adapt to or recover from illness. According to this model, self-care is considered as an action having pattern and sequence and, when performed effectively, contributes in specific ways to human structural integrity, functioning, and development. It is conceptualized as a deliberate action, that is, a purposeful goal- or result-seeking activity. Human beings are conceptualized as intrinsically active rather then passive or even strictly reactive in response to stimuli. They are agents who act deliberately to attain ends or goals (Orem, 2001, p.65). Nurses, who are the primary health care providers discussed in this model, function to educate and facilitate patients in achieving their self-care needs (Hill & Smith, 1985). From a nursing point of view, human beings are viewed as needing continuous self-maintenance and self-regulation through a type of action named self-care (Orem, 2001, p.42).

The self-care model is a complex framework encompassing several concepts and three major theories: self-care deficit theory, theory of self-care, and theory of nursing systems. Self-care deficits are health-related or health-derived limitations that render a person incapable of effective or complete self-care. The theory of self-care stipulates that self-care and care of dependent family members are learned behaviors that purposely regulate human structural integrity, functioning, and human development. The theory of nursing systems suggests that the nursing system is the product of nursing practice through which the patient's ability for self-care is regulated (Dennis, 1997, p.8; Orem, 2001, p.142; Steiger & Lipson, 1985, p.20).

One concept central to Orem's model is "self-care agency". Self-care agency refers to the capabilities of individuals to perform actions to take care of themselves (Orem, 2001, p.254). A person's ability to perform self-care and the amount of self-care that is required are influenced by ten internal and external factors that are called "basic conditioning factors". These basic conditioning factors include age, gender, developmental state, health state, sociocultural orientation, health care system factors, family system factors, patterns of living, environmental factors, and resource availability.

Orem also proposed that the purpose of self-care is to meet what she called "therapeutic self-care demand," which refers to "a summation of measures of self-care required at moments in time and for some time duration by individuals in some location to meet self-care requisites particularized for individuals in relation to their conditions and circumstances" (p. 491). When a person's ability to perform self-care (self-care agency) is not sufficient to meet his or her therapeutic self-care demand, a deficit of self-care exists (Fawcett, 1995; Orem, 2001). Three types of self-care requisites constitute the therapeutic self-care demand: universal, developmental, and health-deviation. Universal self-care requisites are activities, such as obtaining sufficient water or food, which are required by all people during all stages of the life cycle to maintain life functions. Developmental self-care requisites are the requirements related to developmental processes, acquired conditions (e.g., pregnancy), or conditions associated with particular events (e.g., death of a family member). Health-deviation self-care requisites are those needs related to (1) illness, injury, defect or disability or (2) prescribed medical treatment. These requisites represent new or different action demands that may be temporary or of long-term duration; they are not normally present in the absence of illness, injury, disability, or disease (Steiger & Lipson, 1985, p.21).

In her discussion of self-care related to symptoms, Orem suggested that universal and health-deviated self-care requisites are relevant concepts for discussing the impacts of therapy side effects and disease symptoms on patients' self-care. When health status changes due to illness or injury occurrance, new needs and care measures (health-deviation self-care requisites) emerge. Individuals will typically first acknowledge something being wrong (i.e., a symptom) and seek ways to remedy the problem. In response to such problems, persons look to their own knowledge and actions or seek assistance from external sources when they can no longer address the problem themselves. Health deviation self-care requisites also connect with the universal self-care requisites. The changes from health deviations often affect life functioning as well (Dennis, 1997, p.52). For example, when an HIV infected patient experiences the symptom of diarrhea, he or she needs to take additional anti-diarrhea medications (health deviation self-care requisites) and adjust the type of food intakes on his/her behalf (universal self-care requisites).

In HIV/AIDS care, patients' ability to perform self-care is significant in managing symptoms and coping with the disease progression. Despite its wide application among cancer patients and other chronically ill patients, relatively few studies adapted Orem's model in HIV self-care. Concepts from the model have been used as frameworks in some investigations related to HIV patients' self-care abilities and demands. Universal self-care demand and health-deviation self-care demand were used as criteria to indicate the types and burden levels of self-care activities among HIV positive women (Anastasio et al., 1995). Patterns of self-care were examined in terms of their relations to acquired information and symptoms in HIV homosexual/bisexual men (Lovejoy et al., 1992). To maintain the optimal level of quality of life, acquiring self-care ability and knowledge is important for HIV/AIDS patients' disease management. Orem's self-care theory could be helpful as a guide for explaining and exploring the process and determinants of self-care ability enhancement. More studies are needed to test the appropriateness of Orem's theory in the HIV population.

Outcomes Model

The Outcomes Model for Health Care Research proposed by Holzemer (1994), based on the work by Donabedian (1982), provides a useful model for synthesizing the related concepts and identifying potential factors to HIV/AIDS self-care practice.

The Outcomes Model for Health Care Research is a three by three matrix scheme to help organize variables of interest. This framework focuses on inputs, processes and outcomes for evaluating quality of care in the dimensions of clients, providers and settings. The researcher can place the variables of interest in this model, and to explore all of the different types of variables that might be related to the inputs, process and outcomes. In the process of completing the outcomes model, the researcher may also identify a new variable not thought about before and this would require a new literature search. The process can be continued until one has identified as many relevant variables as possible (Holzemer, 1998).

In this study, the variables of interest are HIV/AIDS patients' self-care strategies and its relationships with individual and socioeconomic factors. The identified variables are listed and organized following the Outcomes Model as shown in Figure 1.

Figure 1.

Outcomes Model of Selected Variables in HIV/AIDS Self-Care Strategies

	Inputs	Processes	Outcomes
Clients	Personal characteristics: age, race, gender, use of injection drug, education, income status, and insurance status Disease characteristics: symptom characteristics and use of antiretroviral agents	Self-care Strategies	
Providers			
Settings			

CHAPTER 3 METHODOLOGY

Research Questions

The research questions of the study were:

1. What are the categories of self-care strategies across all types of symptoms that are inductively derived from reports of people living with HIV/AIDS?
2. What are the categories of self-care information resources where people living with HIV/AIDS learn their self-care strategies?
3. Are there differences in the proportions of using newly developed categories of self-care strategies learned from each type of information resource?
4. Are there differences in the newly developed categories of self-care strategies among the top six frequently reported symptoms?
5. Are there differences in personal characteristics, disease characteristics, newly developed self-care strategy categories and newly developed information resources between web-based surveys and interview surveys?
6. Are there relationships among personal characteristics, disease characteristics and newly developed self-care strategy categories in HIV/AIDS patients?

Design

This study was a descriptive, correlational, secondary analysis. This analysis used data from a study supported by grant IS99-SF-215 from the Universitywide AIDS Research Project, University of California, "Symptom Management for Persons with HIV Disease" (April, 1999~March, 2000), William L. Holzemer, Principal Investigator.

Setting/Sample

A convenient sample of HIV-positive persons was recruited from one web site (http://hivsymptoms.ucsf.edu) as well as university-based AIDS clinics, private practices, public and for-profit hospitals, residential and day care facilities, community-based organizations, and home care agencies located in Boston, MA, New York, NY, Oslo, Norway, Paterson, NJ, and the San Francisco Bay Area. On the web site, subjects included self-identified HIV positive patients, caregivers, and health care workers. On outpatient sites, HIV positive patients were recruited as subjects. Data from the patients of all settings collected from July 1999 to February 2000 were used for this secondary analysis. The unit of analysis in the sample was the survey that was completed based on each symptom identified by respondents. A participant could have responded to the questionnaire more than once if he/she had identified more than one symptom. In sum, there were 422 surveys of symptoms in the sample.

On the web site, people who viewed the web page and identified themselves as HIV positive could participate in the study. There were no consent forms for the web-based subjects. The only criterion for admission to the study was the respondents' ability to use computers. On the outpatient sites, people who were 18 years and older with HIV positive status and who provided informed consent using an English consent form were recruited. All patients from the outpatient settings consented to participate in the study, and permission to recruit subjects was received from each participating site as well as from the University of California, San Francisco.

Data Collection Methods

People who read the web site were invited to complete the study. If they chose to participate, they were asked if they were: a person living with HIV/AIDS, a HIV/AIDS caregiver, or a HIV/AIDS health care worker. At the clinic sites, HIV positive patients were approached by interviewers and were asked whether they agreed to complete the surveys. All participants were asked to sign a consent form, complete a demographic questionnaire, and respond to questions related to symptom management strategies. The participants identified a symptom, described it, rated its intensity and bothersomeness, and then responded to three open questions: What do you do to help relieve this symptom? How does it help? Where did you learn this strategy?

Procedure

Besides functioning as a site fot subject recruitment and survey distribution, the web site also serves as the data bank for this study. Data from paper-and-pencil surveys were entered onto the web site. To obtain the aggregate data, the database on the web was downloaded into Microsoft Access^{TM} software. The data set was examined and cleaned. For the purpose of this secondary analysis, the database was transformed into SPSS^{TM} files for quantitative data analysis, MS Word^{TM} files for analysis of the descriptions of self-care strategies, and MS excel files for assisting the coding process.

Data Analysis

Data analysis procedures are described and organized according to the sequence of proposed research questions. The research questions and data analyses are summarized into three phases based upon the unit of analysis used in data analysis. In phase one (question one and two), the unit of analysis was the episode or event related to self-care strategies and self-care information resources. In phase two (question three and four), the unit of analysis was the survey completed according to each symptom. In phase three (question five and six), the unit of analysis was the individual participated in the study. The summary of analytic strategies used in each phase is shown in Table 1.

Table 1.

Unit of Analysis and Analytic Strategies Used in Each Phase of Analysis.

	Research Questions	Unit of Analysis	Analytic strategy
Phase I	1. What are the categories of self-care strategies across all types of symptoms that are inductively derived from reports of people living with HIV/AIDS?	Event or episode (related to self-care strategy and source of self-care information	Content analysis Frequency Inter-rater reliability
	2. What are the categories of self-care information resources where people living with HIV/AIDS learn their self-care strategies?		
Phase II	3. Are there differences in the proportions of using newly developed categories of self-care strategies learned from each type of information resource?	Survey (completed based on reported symptom)	McNemar test Chi-square test
	4. Are there differences in the newly developed categories of self-care strategies among the top six frequently reported symptoms?		

<u>Phase III</u>	5. Are there differences in personal characteristics, disease characteristics, newly developed self-care strategy categories and newly developed information resources between web-based surveys and interview surveys?	Individual	t-test Chi-square test Logistic regression
	6. Are there relationships among personal characteristics, disease characteristics and newly developed self-care strategy categories in HIV/AIDS patients?		

Phase I

Question 1: *What are the categories of self-care strategies across all types of symptoms that are inductively derived from reports of people living with HIV/AIDS?*

To inductively generate a classification scheme of self-care strategies, content analysis was used to identify the themes and categories. Content analysis was a research technique to yield inferences from essentially verbal, symbolic, or communicative data. It was a method of inquiry into symbolic meaning of messages (Krippendorff, 1980). The referential units, which were defined by Krippendorff (1980) as analytic units that may be particular objects, events, persons, acts or ideas to which an expression refers (p. 61), were used as the type of analytic unit for this content analysis process. Therefore, the events and actions that were described for self-care or relieving symptoms were the analytic units for analyzing each description of self-care strategies in each survey.

Initial opening coding and categories of self-care strategies were identified inductively from the data. Events of self-care strategies in the opening coding process were entered in the MS Excel file to summarize their frequencies. Similar activities were than consolidated into larger categories as different types of self-care strategies based on their theoretical similarities and frequencies. Additionally, categories were renamed and regrouped after consulting a group of experts in the field. Once the categories were decided, data of self-care strategies were coded based on the newly developed categories of self-care strategies in the SPSS file for next step analysis.

Question 2: What are the categories of self-care information resources where people living with HIV/AIDS learn their self-care strategies?

Content analysis was also used as the analytic technique for categorizing self-care information resources. Each phrase related to source of information was the unit for analysis. The analytical process was similar to what have been done for the analysis of self-care strategies. Episodes related to self-care information resources were also first entered into a MS excel file to summarize their frequencies. Similar resources of information were than consolidated into larger categories as different categories of self-care information resources based on their theoretical similarities and frequencies. In addition, categories were renamed and regrouped after consulting a group of experts in the field. Once the categories were decided, data of self-care information resources were coded in the SPSS file.

Validity and Reliability of Coding Schemes

The validity of coding scheme for self-care strategies and self-care information resources was established by content validity. Panels of experts in HIV/AIDS care and health care research were invited to review the coding schemes summarized by the investigator. The reliability of coding scheme was determined by inter-rater reliability to estimate equivalence.

Two raters with backgrounds of nursing care and research but have not been involved in the original project were invited in the reliability testing process. Both raters had never seen the data set before. The first rater was given 25% of the data that was randomly selected from the whole data set to read the raw data of self-care strategies and code them based on the newly developed categories. After the coding was finished, the results were compared with what the investigator had already coded for the same subset of data to compare the inter-rater reliability of categories for self-care strategies. The second rater was given another set of 25% of the data that was also randomly selected from the whole data set to read and code the self-care information resources based on the newly developed categories of information resources. Similarly, after the coding was completed, the results were compared with what the investigator had been coded for the same subset of data. Cohen's Kappa statistics were obtained to determine the level of agreement (Downe-Wamboldt, 1992).

Phase II

Question 3: Are there differences in the proportions of using newly developed categories of self-care strategies learned from each type of information resource?

New variables were generated according to newly developed categories for both self-care strategies and self-care information resources. Since multiple self-care strategies and information resources could be selected in each survey, the variables of self-care strategies and information resources were both considered as multiple response items. Multiple dichotomy method was used for variable mapping, which creates a individual variable in SPSS file for each type of self-care strategy and assign dichotomous coding as yes and no. For the purpose of this analysis, the first step was creating dichotomous variables for newly developed self-care strategies.

Within each type of self-care strategy, the second step was to further create dichotomous variables of information resource that used for this particular type of self-care strategy. For example, an individual variable was created for self-comforting strategy and each datum was coded as either yes or no. Four additional dichotomous variables were further created for four types of information resources used in self-comforting strategy (e.g., self-comforting strategy with self as information source, self-comforting strategy with personal network as information source, self-comforting strategy with community as information source, and self-comforting strategy with health care provider as information source). Therefore, there were 32 new variables created (four types of information resources × eight self-care strategies).

To compare the proportions of self-care strategies used among different information resources, multiple 2 by 2 cross-tab tables and McNemar tests were used to compare the proportion of each kind of self-care strategy learned from each type of information resource. Since more than one type of self-care strategy could be reported from one information resource, McNemar test was used for comparing the differences in proportions of self-care strategies used between two types of information resources. McNemar test is a nonparametric test used for analyzing changes that occur in dichotomous variables in 2 × 2 table. It is appropriate for repeated measures such as match-paired comparison, or pretest/posttest comparisons (Burns & Grove, 1997, p. 473). For the purpose of this research question, it was considered that this test was appropriate for analyzing the non-independent observations in dichotomous variables of the study.

The cases which reported "yes" in each self-care strategy (e.g., medication strategy) were first selected and then comparisons were made across resources of self-care information to determine the proportion of using this particular strategy (e.g., medication strategy) within each information resource. For each type of self-care strategy, three 2 by 2 McNemar tests were performed for comparisons among self and other three kinds of information resources (i. e., medication with self as information source * medication with personal network as information source; medication with self as information source * medication with community as information source; medication with self as information source * medication with health care worker as information source). The same procedures were done for each self-care strategy. Therefore, there were 24 2 by 2 McNemar tests performed. To avoid the problem of galloping alpha, the level of significance (alpha) was adjusted and set as .017(.05 divided by 3).

Question 4: Are there differences in the newly developed categories of self-care strategies among the top six frequently reported symptoms?

The top six frequently reported symptoms were determined by running frequency reports of all reported symptoms. One new categorical variable was created to code whether one of the six symptoms was reported (1-6).

Within each type of self-care strategy, 2 by 6 Chi-square test was used to test the difference in proportions of this type of self-care strategy among the six symptoms (yes/no for each strategy among six symptoms). Therefore, eight Chi-square tests were performed for eight types of self-care strategies. The level of significance (alpha) was adjusted and set as .006 (.05 divided by 8).

Phase III

Question 5: Are there differences of personal characteristics, disease characteristics, newly developed self-care strategy categories and newly developed information resources between web-based surveys and interview surveys?

After the phase II analysis, the data set was cleaned and transformed to use each participant as the unit of analysis in the phase III analysis. The phase II data were first sorted by age. Secondly, surveys from the same participant were identified by checking whether there were same personal information reported (race, gender, living city and state, and e-mail address). When there were more than one survey from one participant, the coding of self-care strategy and self-care information were combined into the first survey and the second or more symptom surveys were deleted. After the data cleaning, each participant was assigned a new study ID for Phase III data set.

To compare the personal characteristics and disease characteristics between web-based subjects and interview subjects, independent sample t-test was used to compare the difference in continuous variables (age, CD4 count) and 2 by 2 Chi-square test was used to test the difference in categorical variables (gender, race, education, injection drug use, taking antiretroviral medications, and given AIDS diagnosis).

To compare the use of self-care strategy and self-care information resources between web-based subjects and interview subjects, multiple 2 by 2 Chi-square tests were used to test the difference in the proportion of each category.

Question 6: Are there relationships among personal characteristics, disease characteristics and newly developed self-care strategy categories in HIV/AIDS patients?

The hierarchical logistic regression model technique was used for analyzing data when the outcome variable was a categorical variable (self-care strategy). Multiple logistic regressions were performed to generate regression models among the set of identified explanatory variables and each type of self-care strategy (Long, 1997). Eight logistic regressions were conducted to test predictive models of eight categories of self-care strategies.

Eleven variables related to personal characteristics and disease characteristics were selected and entered into the analysis in two steps. The first block of variables were variables of personal characteristics including: 1) age (continuous variable); 2) gender (0 = male, 1 = female); 3) race (0 =White, 1 = not White); 4) Education (0 = greater than high school, 1 = less than high school); 5) injection drug use (0 =never use, 1 = former/ current user); 6) insurance status (0 = inadequate, 1 = barely enough/enough); 7) income status (0 = inadequate, 1 = barely enough/enough). The second block of variables were variables of disease characteristics including: 1) taking antiretroviral medications (0 = yes, 1 = no); 2) symptom intensity (continuous variable, 1-10); 3) symptom bothersomeness (continuous variable, 1-10); 4) symptom affects daily life (continuous variable, 1-10). The dependent variable was each type of self-care strategy (0 = not using, 1 = yes).

Protection of Human Subjects

Approval from Committee on Human Subjects at UCSF had been obtained for the original study (# H642-16172-01A, April 28, 1999). For the purpose of secondary analysis in this study, exempt certification has also been filed and approved at CHR of UCSF on November 14, 2001.

CHAPTER 4 RESULTS

This chapter presents a summary of the results of this study, based on each research question.

Question 1: What are the categories of self-care strategies across all types of symptoms that are inductively derived from reports of people living with HIV/AIDS?

Coding Process and Categories of Self-Care Strategies

In this study, eight hundred and six episodes related to self-care strategies that were described in the surveys were identified, and 20 codes from an initial open coding process were summarized. The frequencies and examples of these 20 coding categories are shown in Table 2. In order to reduce the number of categories, these codes were consolidated into eight larger categories after repeated modification and consultation from a panel of experts based on their theoretical similarities and clinical significance. Another decision criterion of the grouping was that the frequency of each larger category had to be at least 50. For example, all activities related to using therapeutic equipment and taking medications (prescribed and over-the-counter), including changing the routine of taking medicines, were grouped into one larger category. Activities that related to changing foods and eating habits were grouped into another category. Figure 2 shows the grouping process and the final eight categories resulting from these initial codes.

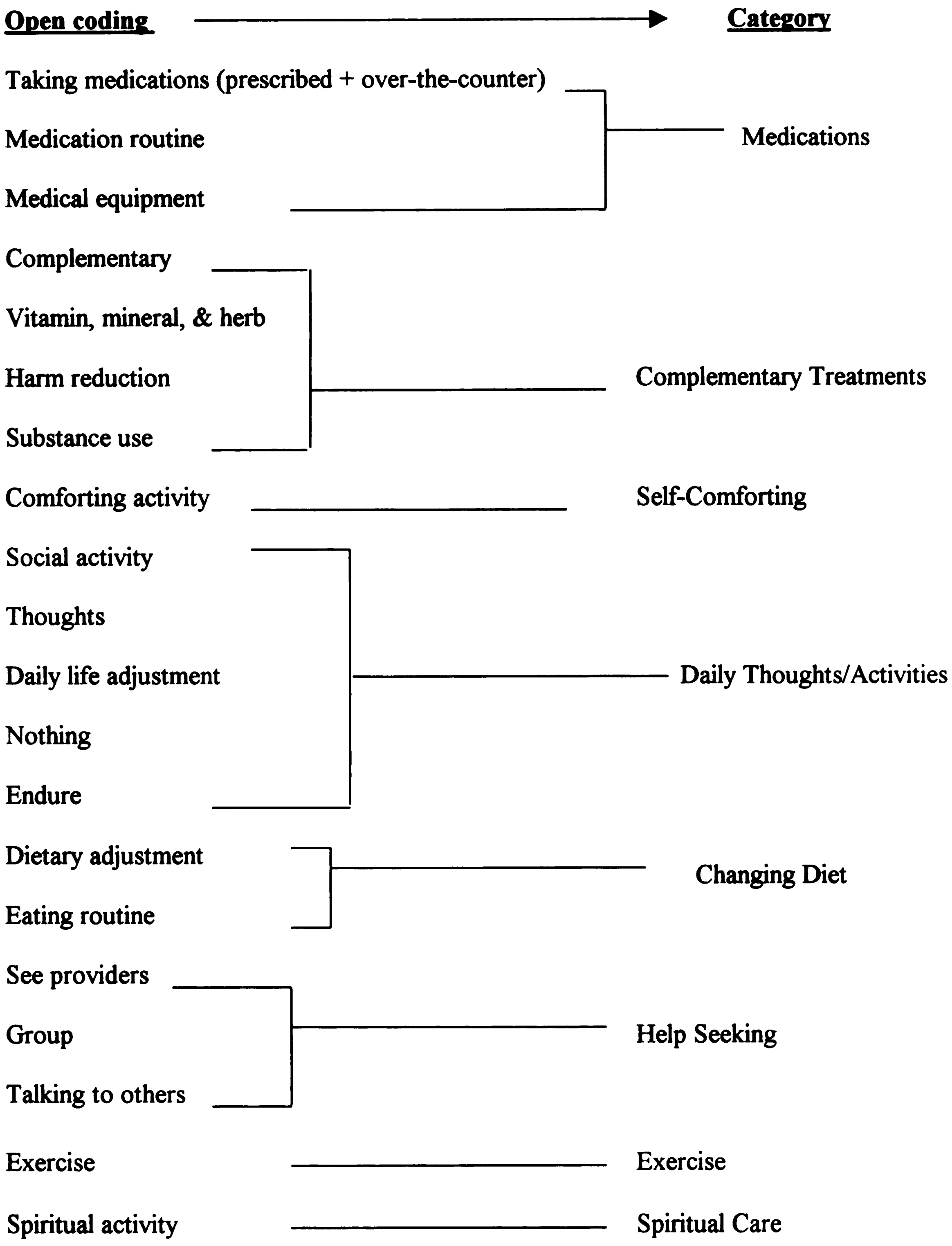
Table 2.

Frequencies and Examples of Initial Coding for Self-Care Strategies.

Type	Examples	Frequency
Taking medications (prescribed and over-the-counter)	Neurondin™, Imodium™ (over-the-counter)	168
Medication routine	take meds with foods, skip a dose of meds occasionally	15
Medical equipment	pain releasing machine (TENS)	1
Complementary	acupuncture, meditation, massage	43
Vitamin, mineral & herb	glutamine, acidophilus, herbal products, marijuana	52
Harm reduction	stop getting high	1
Substance use	use Heroin, drink alcohol, smoke cigarettes	27
Comforting activity	sleep, go to a hot tub, nap when I am tired, read a book, cry	119
Social activity	working, go out of the house	27
Thoughts	not to think about it, think about something else, talk to myself	29
Daily life adjustment	keep busy by cleaning, left work, stay near bathrooms	27
Nothing	I did nothing about it	16
Endure	learn to live with it, wait for it to go away	6
Dietary adjustment	eat lots of fiber, avoid caffeine, watch the diet	74
Eating routine	eating binge, stay away from foods, stop eating	13
See providers	see doctor, go to the hospital, physical therapy	28
Group	attend group therapy, attend support group	16
Talking to others	mother, friends, people with HIV	39
Exercise	work out, walking, jogging, gardening	52
Spiritual activity	pray, talk to dead people (grandma), go to church, bible	53
Total		806

Figure 2.

Grouping Process for Categories of Self-Care Strategies



The eight categories of self-care strategies were: medications, complementary treatments, self-comforting, daily thoughts/activities, changing diet, help seeking, exercise, and spiritual care. The author based her definitions of these self-care categories on the nature of strategies in each category (see Table 3). All events related to self-care strategies in the data set were recoded according to these eight newly developed categories, and the frequencies were recalculated according to the eight categories. In each survey, if there were two activities belonging to the same category, they would be only counted once in the frequency calculation. For example, one survey listed both “seeing providers” and “talking to others” as self-care strategies. In this study, however, both these activities were subsumed in the help-seeking category and were coded as help seeking. However, because both came from the same survey, they were only counted as one help-seeking activity instead of two in the frequency calculation. The reason for doing this was to avoid redundancies of data. Therefore, the total number of self-care strategies after coding with the eight categories was less than the number of self-care strategies obtained from the initial 20 codes. Recoding the data according to these eight categories yielded a total of 776 reported self-care strategies. The most frequently used type of self-care strategy was medications (23.45%), and the least frequently used type of self-care strategy was exercise (6.70%; see Table 4).

Table 3.

Definitions of Categories of Self-Care Strategies

Category	Definition
Medications	All activities include taking any prescribed, over-the-counter medications, or using medical equipment.
Self-Comforting	All activities that people create or perform particular actions to comfort themselves or relieve the symptoms.
Complementary Treatments	All activities include using complementary/ alternative therapies, vitamin, mineral, herbs, or some substances to release the symptoms.
Daily Thoughts/Activities	All activities related to what people adjust in their daily life routine or change their thoughts in order to make themselves feel better.
Changing Diet	All activities include what people do to adjust their diet habits, eating routine, or foods.
Help Seeking	All activities that people ask and talk to someone (professionals or lay persons), or attend some group sessions.
Spiritual Care	All activities related to spiritual level of interaction
Exercise	All activities have exercising benefits ranging from mild, moderate to intense level of exercise.

Table 4.

Frequencies of Self-Care Strategies (Unit of Analysis: Event of Self-Care Activity)

Self-Care Strategy	**n (%)**
Medications	182 (23.45%)
Self-Comforting	118 (15.21%)
Complementary Treatments	114 (14.69%)
Daily Thoughts/Activities	100 (12.89%)
Changing Diet	85 (10.95%)
Help Seeking	72 (9.28%)
Spiritual Care	53 (6.83%)
Exercise	52 (6.70%)
Total	776 (100%)

Validity and Reliability Testing for Categories of Self-Care Strategies

Content validity of categories for self-care strategies was established after a panel of experts reviewed the categories that were first summarized by the investigator. Reliability of coding was presented in inter-rater reliability tests. Twenty-five percent of the surveys were randomly selected (n = 112) from the total number of survey for testing the inter-rater reliability between two raters. The results show that the values of Cohen's Kappa of categories for self-care strategies range from .49 to .93 and percents of agreement range from 88% to 100% (Table 5). These results show moderate agreement to almost perfect agreement in coding and the agreement is significantly different from chance agreement (Landis & Koch, 1977).

Table 5.

Inter-rater Reliability Testing of Categories for Self-Care Strategies

	n	Percent of Agreement (%)	Cohen's Kappa	*p*
Medications	112	95%	.89	.000
Self-Comforting	112	93%	.83	.000
Complementary Treatments	112	95%	.85	.000
Daily Thoughts/Activities	112	88%	.49	.000
Changing Diet	112	95%	.84	.000
Help Seeking	112	96%	.89	.000
Spiritual Care	112	100%	1.00	.000
Exercise	112	98%	.93	.000

Question 2: What are the categories of self-care information resources where people living with HIV/AIDS learn their self-care strategies?

Coding Process and Categories of Self-Care Information Resources

Six hundred and five episodes and 10 opening codes of sources for self-care information were identified in the initial coding process (see Table 6). These opening codes were collapsed into four larger categories after consulting with a panel of experts and repeated revision (Figure 3). The four categories of self-care information resources were: self, personal network, community, and health care provider. The author defined these categories based on the common meanings of these information resources in each category (see Table 7). All the reported events related to self-care information resources in the data set were then recoded in a manner similar to that used to analyze the self-care strategies above. In each survey, if there were two data points belonging to the same category, they would be only counted once in the frequency calculation. Recoding the data based on these four categories yielded a total of 526 items of data pertaining to self-care information resources. The most frequently reported resource of self-care information was the self (34.41%), and the least frequently reported resource of self-care information was the community (18.44%; Table 8).

Table 6.

Frequencies and Examples of Initial Coding for Self-Care Information Resources

Type	**Examples**	**Frequency**
Experience	from my childhood, from my own experience overtime, life, my training, just apply previous experience	59
Myself	on my own, myself, I figure it out myself, I just pick it up, my mind tells me, just happens	104
Trial and error	I developed it myself, through personal observation, personal research, try whatever is good for me	34
Common sense	from my common sense	3
Peers & others	from other sufferers, my friends, street knowledge, church, words of mouth, God	75
Family member	Grandmother, spouse, my partner comes up with it, mom	44
Community programs	Local AIDS program, support group, YMCA, medical seminars, courses, work place	61
Literature and reading	Read about it, books, health magazines, literature, newsletters	41
Media	searched the net, Internet-based sources, from a online newsgroup, from a TV program	22
Health care provider	My clinic, from my doctor, advised by my psychiatrist, nutritionist, acupuncturist, my nurse practitioner	162
Total		605

Figure 3.

Grouping Process for Categories of Self-Care Information Resources

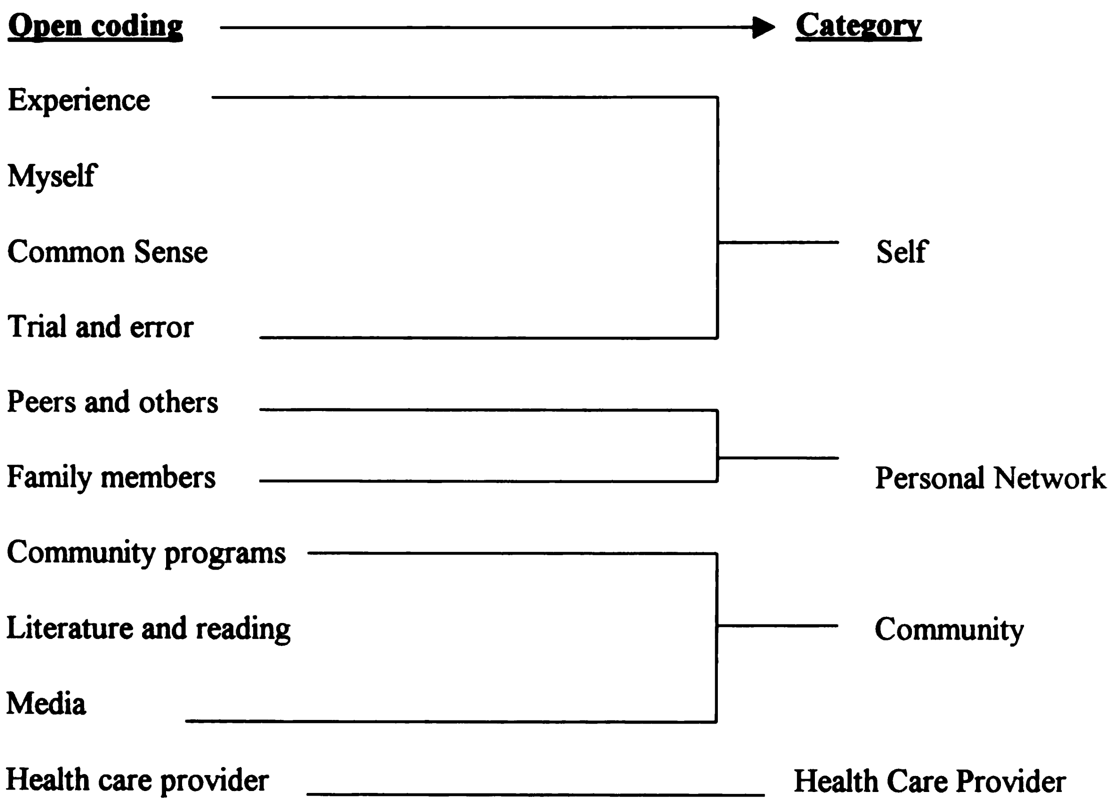


Table 7.

Definitions of Categories of Self-Care Information Resources

Type	**Definition**
Self	The person himself/herself is the source of information for self-care. This may include a person's own experience, trial and error, and self-experiment.
Personal Network	This refers to learning information from someone close to own personal family and social network. Relatives, friends or other peers are examples.
Community	Community includes all resources from a person's external environment, such as reading, media, or community groups.
Health Care Provider	Health care providers include all types of professionals or settings that a person seeks for and receive health care. Professionals who work in alternative therapies are not excluded.

Table 8.

Frequencies of Self-Care Information Resources (Unit of Analysis: Event of Information Resource for Self-Care

Self-Care Information Resources	n (%)
Self	181 (34.41%)
Health Care Provider	147 (27.95%)
Personal Network	101 (19.20%)
Community	97 (18.44%)
Total	526

Validity and Reliability Testing for Categories of Self-Care Information Resources

Content validity of categories for self-care information resources was established after a panel of experts reviewed the categories that were first summarized by the investigator. Reliability of coding was presented in inter-rater reliability tests. One fourth of the surveys were randomly selected (n = 99) from the total number of surveys in order to test the inter-rater reliability between two raters. The results showed that the values of Cohen's Kappa range from .70 to .87, and percents of agreement range from 87% to 95% (see Table 9). These results show moderate to substantial agreement in coding, which is a level significantly higher than chance agreement (Landis & Koch, 1977).

Table 9.

Inter-rater Reliability Testing for Categories of Self-Care Information Resources

	n	Percent of Agreement (%)	Cohen's Kappa	*p*
Self	99	91%	.82	.000
Health Care Provider	99	93%	.85	.000
Personal Network	99	95%	.87	.000
Community	99	87%	.70	.000

Question 3: Are there differences in the proportions of using newly developed categories of self-care strategies learned from each type of information resource?

The health care provider was the most frequently reported information source for medication strategy (n = 107, 63%). The self was the most frequently reported information source for most self-care strategies: complementary treatments (n = 54, 48%), self-comforting (n = 86, 86%), daily thoughts/activities (n = 56, 73%), changing diet (n = 47, 57%), help seeking (n = 52, 72%) and exercise (n = 29, 59%). The personal network was the most frequently used information source for the spiritual care strategy (n = 40, 76%). Table 10 shows the McNemar tests for comparing the use of each self-care strategy in personal network, community, and health care provider as information source with the use of self as information source. The self was chosen as the baseline for comparison because it was the most frequently reported source of self-care information. The results show significant differences in the proportions of using self-care strategy across information resources for most self-care strategies, except changing diet and exercise.

Table 10.

Comparisons of Proportions in Using Self-Care Strategies with Different Self-Care Information Resources (Total Sample Size N = 422; Unit of Analysis = Each Survey Completed Based on Each Symptom)

	Self	Personal Network	Community	Health Care Provider
Self-Care Strategy	n(%)	n(%)	n(%)	n(%)
Medications (n = 171)	78(46%)	44 (26%)*	37 (22%)*	107 (63%)*
Self-Comforting (n = 114)	86 (75%)	44 (39%)*	31 (27%)*	40 (35%)*
Complementary Treatments (n = 112)	54 (48%)	34 (30%)*	51 (46%)	40 (36%)
Daily Thoughts/Activities (n = 77)	56 (73%)	34 (44%)*	18 (23%)*	26 (34%)*
Changing Diet (n = 82)	47 (57%)	32 (39%)	28 (34%)	34 (42%)
Help Seeking (n = 72))	52 (72%)	41 (57%)	26 (36%)*	40 (56%)
Spiritual Care (n = 53)	38 (72%)	40 (76%)	14 (26%)*	29 (55%)
Exercise (n = 49)	29 (59%)	19 (39%)	23 (47%)	17 (35%)

* Significant 2 by 2 McNemar tests when comparing to the proportion in using self as information source for each self-care strategy (first column), level of significance: alpha = .017 (.05 divided by 3).

Question 4: Are there differences in the newly developed categories of self-care strategies among the top six frequently reported symptoms?

There were a total of 31 types of symptoms reported, and the six most frequently reported symptoms among the 422 symptom surveys were anxiety/fear (n = 74), diarrhea (n = 70), neuropathy (n = 49), nausea/vomiting (n = 41), depression (n = 34), and fatigue (n = 31). Only the cases which reported one of the six symptoms were included for the analysis of this research question (n = 286). Table 11 shows the proportion of each self-care strategy across the six symptoms. Among survey respondents reporting diarrhea symptoms, the self-care strategies of medication (n = 43, 62%) and changing diet (n = 36, 52%) had the highest proportion of use. Survey respondents reporting nausea/vomiting symptoms used the self-comforting strategy (n = 19, 49%) most frequently. Daily thoughts/activities were mostly used among those reporting depression (n = 15, 44%). Help seeking (n = 30, 44%) and spiritual care (n = 22, 42%) were most frequently used for anxiety/fear. Exercise was mostly used for the symptom of fatigue (n = 12, 40%). Chi-square tests show that except for the category of complementary treatments, there were significant differences in the proportion of most types of self-care strategies used among the six symptoms.

Table 11.

Comparisons of Proportions in Using Self-Care Strategies among the Top Six Frequently Reported Symptoms (Total Sample Size N = 286; Unit of Analysis: Each Survey Completed by Each Symptom)

	Anxiety/Fear	Diarrhea	Neuropathy	Nausea/Vomiting	Depression	Fatigue	Chi-square
	(n = 68)	(n = 69)	(n = 46)	(n = 39)	(n = 34)	(n = 30)	(df = 5)
Self-Care Strategy	n(%)	n(%)	n(%)	n(%)	n(%)	n(%)	$\chi^2(p)$
Medications	23 (34%)	43 (62%)	25 (54%)	17 (44%)	13 (38%)	2 (7%)	31.74 (.000)
Complementary Treatments	22 (32%)	16 (23%)	23 (50%)	12 (31%)	8 (24%)	5 (17%)	13.68 (.018)
Self-Comforting	23 (34%)	4 (6%)	12 (26%)	19 (49%)	12 (35%)	14 (47%)	31.31 (.000)
Daily Thoughts/ Activities	29 (43%)	11 (16%)	5 (11%)	5 (13%)	15 (44%)	8 (27%)	28.53 (.000)
Changing Diet	4 (6%)	36 (52%)	1 (2%)	18 (46 %)	2 (6%)	2 (7%)	79.89 (.000)
Help Seeking	30 (44%)	10 (15%)	4 (9%)	1 (3%)	14 (41%)	2 (7%)	47.35 (.000)
Exercise	16 (24%)	1 (1%)	4 (9%)	1 (3%)	9 (27%)	12 (40%)	38.12 (.000)
Spiritual Care	22 (42%)	3 (4%)	2 (4%)	3 (8%)	11 (32%)	2 (7%)	37.52 (.000)

*Level of significance: alpha = .006 (.05 divided by 8).

Question 5: Are there differences of personal characteristics, disease characteristics, newly developed self-care strategy categories and newly developed information resources between web-based surveys and interview surveys?

Demographic Characteristics of the Whole Sample

After the data file was converted by using participant as the unit of analysis, there were 359 subjects in the phase III analysis data set. The mean age was 42.7 years old. Seventy-eight percent of the sample was male, and thirty-seven percent lived alone. The distribution of ethnicity was: White (47%), African American (35%), Latino (13%), and other (5%). Thirty-eight percent of the sample had an education level less than high school, and thirty-two percent of the participants were former or current users of injection drugs. Thirty-seven percent of the sample had been diagnosed with AIDS, and seventy-four percent of the participants were taking antiretroviral medications (see Table 12).

Table 12.

Characteristics of the Sample (N = 359)

Variables	M (Range)	SD	f	%
Age	42.7 (15-79)	9.79		
CD 4 count	411.1 (0-1488)	278.30		
Symptom Intensity	6.8 (1-10)	2.45		
Symptom Bothersomeness	7.2 (1-10)	2.67		
Symptom Affecting Daily Life	6.4 (1-10)	2.91		
Number of Reported Symptoms	1.2 (1-6)	.54		
Gender				
Male			278	77.4%
Female			79	22.0%
Race				
White			168	46.8%
Black or American African			127	35.4%
Latino/Hispanic			45	12.5%
Asian			6	1.7%
Other			8	2.2%
Education				
Greater than high school			218	60.7%
High school or less			137	38.2%

Web-Based Subjects versus Interview Subjects

In this study, 122 subjects completed web-based surveys and 237 subjects completed interview surveys. Tables 13 and 14 provide graphic comparison of personal characteristics (age, gender, race, education, and injection drug use) and disease characteristics (having AIDS diagnosis, taking antiretroviral medications, and CD4 count) for web-based subjects versus interview subjects. The results demonstrate that the sample in the web-based surveys was significantly younger, better educated, had a higher number of Whites, fewer injection drug users, and a higher number of people diagnosed with AIDS than the sample in interview surveys.

The differences in use of self-care strategies between web-based subjects and interview subjects are shown in Table 15, and the differences in self-care information resources between web-based subjects and interview subjects are shown in Table 16. The Chi-square test results show that the web-based subjects used significantly less help seeking strategy and spiritual care strategy than the interview subjects. Personal network as self-care information resource was used significantly less often by web-based subjects than by interview subjects.

Table 13.

Comparisons of Personal Characteristics and Disease Characteristics between Web-Based Subjects and Interview Subjects: Continuous Variables

	Web-Based				Interview				
	M	Range	SD	n	M	Range	SD	n	t-test
Age	40.34	15-64	9.78	120	43.88	25-79	9.60	235	3.26*
CD4 count	451.29	1-1100	274.66	93	389.97	0-1488	278.64	177	-1.73

* $p < .05$.

Table 14.

Comparisons of Personal Characteristics and Disease Characteristics between Web-Based Subjects and Interview Subjects: Categorical Variables

Variables	Web-Based n(%)	Interview n(%)	χ^2	*p*
Gender				
Male	104 (86.0%)	174 (73.7%)	6.93	.008
Female	17 (14.0%)	62 (26.3%)		
Race				
White	100 (82.6%)	68 (29.2%)	91.28	.000
Not white	21 (17.4%)	165 (70.8%)		
Education				
Greater than high school	103 (85.8%)	115 (48.9%)	45.63	.000
High school or less	17 (14.2%)	120 (51.1%)		
Injection drug use				
Never used	104 (88.9%)	119 (54.1%)	41.32	.000
Former or current user	13 (11.1%)	101 (45.9%)		
Taking antiretroviral medications				
Yes	86 (74.1%)	180 (76.9%)	.330	.566
No	30 (25.9%)	54 (23.1%)		
Given AIDS diagnosis				
Yes	62 (53.0%)	72 (33.5%)	15.23	.000
No	48 (41.0%)	136 (63.3%)		
Do not know	7 (6.0%)	7 (3.3%)		

* Level of significance: alpha = .05.

Table 15.

Comparisons of Self-Care Strategies between Web-Based and Interview Subjects

	Web-Based	Interview		
	(n = 118)	(n = 218)		
Self-Care Strategy	%	%	χ^2	*p*
Medications	54.2%	46.3%	1.92	.166
Complementary Treatment	29.7%	28.9%	.02	.883
Self-Comforting	24.6%	39.4%	7.52	.006
Daily Thoughts/Activities	22.0%	31.2%	3.19	.074
Changing Diet	22.0%	24.8%	.32	.574
Help Seeking	2.5%	31.2%	37.71	.000
Exercise	11.0%	15.1%	1.10	.294
Spiritual Care	2.5%	22.0%	22.56	.000

*Level of significance: alpha = .006 (.05 divided by 8).

Table 16.

Comparisons of Self-Care Information Resources between Web-Based and Interview Subjects

	Web-Based	Interview		
	(n = 105)	(n = 203)		
Self-Care Information Resource	%	%	χ^2	*p*
Self	50.5%	54.2%	.38	.536
Personal Network	18.1%	37.9%	12.69	.000
Community	27.6%	29.1%	.07	.790
Health Care Provider	34.3%	49.8%	6.71	.010

*Level of significance: alpha = .0125 (.05 divided by 4).

Question 6: Are there relationships among personal characteristics, disease characteristics and newly developed self-care strategy categories in HIV/AIDS patients?

Hierarchical logistic regression was used to estimate the probabilities of each self-care strategy being used, based on selected personal characteristics and disease characteristics. Eleven predictor variables were used in the analysis. Seven variables related to personal characteristics were entered at the first step, and four variables related to disease characteristics were entered at the second. The results of eight logistic regressions for eight types of self-care strategies are shown from Table 17 to Table 24. The values of the variables summarized in the tables are from the block where they were entered. The results show that the overall predictive model was statistically significant in predicting the use of medications (Table 17), self-comforting (Table 19), help seeking (Table 22), and spiritual care (Table 24). However, the predictive model was not statistically significant for the use of complementary treatments (Table 18), daily thoughts/activities (Table 20), changing diet (Table 21), and exercise (Table 23).

As shown in Table 17, the overall predictive model was statistically significant for predicting the use of medications as self-care strategy (Model $\chi^2 = 21.87, p < .05$). Two predictor variables were statistically significant in terms of the likelihood of medications being used as a self-care strategy: race (Wald = 5.15, $p < .05$), and symptom intensity (Wald = 7.14, $p < .01$). Non-white patients were nearly less than half as likely to use medications than white patients were (odds ratio = .55, 95%CI = .33 - .92). The likelihood of using medications was 22 percent greater among those who had higher symptom intensity scores than those had lower symptom intensity scores (odds ratio = 1.22, 95%CI = 1.05 - 1.40). The hierarchical entering of variables shows that variables related to disease characteristics had better prediction (Block 2 $\chi^2 = 15.54, p = .004$) than those variables related to personal characteristics (Block 1 $\chi^2 = 6.33, p = .50$).

The overall predictive model was statistically significant in the use of self-comforting as self-care strategy (Model $\chi^2 = 30.06, p < .05$; see Table 19). Race was the only statistically significant variable in terms of the likelihood of self-comforting being used as a self-care strategy (Wald = 7.37, $p < .05$). Non-white patients were twice as likely to use the self-comforting strategy than white patients were (odds ratio = 2.17, 95%CI = 1.24 - 3.79).

As shown in Table 22, the overall predictive model was statistically significant in the use of the help seeking strategy for self-care (Model $\chi^2 = 58.25, p < .001$). Only one variable, race, was statistically significant in terms of the likelihood of using this strategy for self-care (Wald = 18.23, $p < .01$). Non-white patients were nearly six times more likely to use the help seeking strategy than non-white patients were (odds ratio = 5.71, 95%CI = 2.57 - 12.70).

The overall predictive model was also statistically significant in predicting the use of spiritual care strategy for self-care (Model $\chi^2 = 59.60, p < .001$; see Table 24). Two variables were statistically significant in terms of the likelihood of applying the spiritual care strategy in self-care: gender (Wald = 10.89, $p < .01$) and race (Wald = 9.55, $p < .01$). HIV positive women were more than three times as likely to use this strategy than their male counterparts (odds ratio = 3.76, 95%CI = 1.71 - 8.25), and non-white patients were five times more likely to use it than white patients (odds ratio = 5.09, 95%CI = 1.81 - 14.30).

Table 17.

Logistic Regression: Prediction of the Likelihood of Using Medications as Self-Care Strategy (n = 297)

Predictor Variable	b§	Wald	*p*	Odds Ratio (95% CI)
Block 1				
Age	.01	.82	.36	1.01 (.99 - 1.04)
Gender	.05	.02	.89	1.05 (.56 - 1.95)
Race	-.60	5.15	.02	.55 (.33 - .92)
Education	.31	1.21	.27	1.37 (.78 - 2.39)
Injection drug use	.08	.09	.77	1.08 (.64 - 1.85)
Insurance status	-.02	.00	.96	.98 (.51 - 1.89)
Income status	-.26	.15	.70	.91 (.46 - 1.79)
Block 2				
Taking antiretroviral medications	-.32	1.20	.27	.73 (.41 - 1.29)
Symptom intensity	.20	7.14	.01	1.22 (1.05 - 1.40)
Symptom bothersomeness	-.16	3.67	.06	.85 (.73 - 1.00)
Symptom affects daily life	.13	3.32	.07	1.14 (.99 - 1.30)
-2 Log Likelihood	389.83			
Model Chi-square (df = 11)	21.87	(p = .03)		
Block 1 Chi-square (df = 7)	6.33	(p = .50)		
Block 2 Chi-square (df = 4)	15.54	(p = .004)		

§Unstandardized logistic regression coefficients.
* Level of significance: alpha = .05.

Table 18

Logistic Regression: Prediction of the Likelihood of Using Complementary Treatments as Self-Care Strategy (n = 297)

Predictor Variable	$b^{\S}$	Wald	*p*	Odds Ratio (95% CI)
Block 1				
Age	.01	.31	.58	1.01 (.98 - 1.03)
Gender	-.59	2.25	.13	.55 (.26 - 1.20)
Race	-.31	1.15	.28	.73 (.42 - 1.29)
Education	.23	.51	.48	1.25 (.68 - 2.32)
Injection drug use	-.29	.90	.34	.75 (.41 - 1.37)
Insurance status	-.10	.07	.79	.91 (.43 - 1.89)
Income status	.35	.73	.39	1.42 (.63 - 3.20)
Block 2				
Taking antiretroviral medications	-.02	.00	.96	.98 (.53 - 1.83)
Symptom intensity	.04	.20	.65	1.04 (.89 - 1.21)
Symptom bothersomeness	.10	1.44	.23	1.11 (.94 - 1.31)
Symptom affects daily life	-.08	1.20	.27	.92 (.80 - 1.07)
-2 Log Likelihood	344.10			
Model Chi-square (df = 11)	9.69	(p = .56)		
Block 1 Chi-square (df = 7)	7.46	(p = .38)		
Block 2 Chi-square (df = 4)	2.23	(p = .69)		

§Unstandardized logistic regression coefficients.
* Level of significance: alpha = .05.

Table 19

Logistic Regression: Prediction of the Likelihood of Using Self-Comforting as Self-Care Strategy (n = 297)

Predictor Variable	b§	Wald	*p*	Odds Ratio (95% CI)
Block 1				
Age	-.02	2.29	.13	.98 (.95 - 1.01)
Gender	.49	2.16	.14	1.62 (.85 - 3.10)
Race	.77	7.39	.01	2.17 (1.24 - 3.79)
Education	.04	.02	.90	1.04 (.57 - 1.89)
Injection drug use	-.03	.01	.92	.97 (.54 - 1.73)
Insurance status	-.60	2.99	.08	.55 (.28 - 1.08)
Income status	-.49	1.81	.18	.61 (.30 - 1.25)
Block 2				
Taking antiretroviral medications	-.33	1.04	.31	.72 (.39 - 1.35)
Symptom intensity	-.04	.27	.60	.96 (.82 - 1.12)
Symptom bothersomeness	.09	1.03	.31	1.09 (.92 - 1.29)
Symptom affects daily life	-.00	.00	.96	1.00 (.87 - 1.15)
-2 Log Likelihood	349.40			
Model Chi-square (df = 11)	30.06	(p = .002)		
Block 1 Chi-square (df = 7)	27.43	(p = .000)		
Block 2 Chi-square (df = 4)	2.63	(p = .62)		

§Unstandardized logistic regression coefficients.

* Level of significance: alpha = .05.

Table 20

Logistic Regression: Prediction of the Likelihood of Using Daily Thoughts/Activities as Self-Care Strategy (n = 297)

Predictor Variable	b§	Wald	*p*	Odds Ratio (95% CI)
Block 1				
Age	-.01	.35	.55	.99 (.96 - 1.02)
Gender	.08	.05	.82	1.08 (.54 - 2.16)
Race	.15	.26	.61	1.17 (.65 - 2.11)
Education	.53	2.74	.10	1.69 (.91- 3.16)
Injection drug use	-.25	.64	.42	.78 (.42 - 1.44)
Insurance status	.28	.51	.48	1.32 (.62 - 2.81)
Income status	-.50	1.83	.18	.61 (.29 - 1.25)
Block 2				
Taking antiretroviral medications	-.11	.11	.74	.90 (.47 - 1.72)
Symptom intensity	-.07	.68	.41	.93 (.79 - 1.10)
Symptom bothersomeness	.25	7.82	.01	1.29 (1.08 - 1.53)
Symptom affects daily life	-.13	3.05	.08	.88 (.76 - 1.02)
-2 Log Likelihood	322.24			
Model Chi-square (df = 11)	15.58	(p = .16)		
Block 1 Chi-square (df = 7)	7.30	(p = .40)		
Block 2 Chi-square (df = 4)	8.28	(p = .08)		

§Unstandardized logistic regression coefficients.

* Level of significance: alpha = .05.

Table 21

Logistic Regression: Prediction of the Likelihood of Using Changing Diet as Self-Care Strategy (n = 297)

Predictor Variable	$b^{\S}$	Wald	*p*	Odds Ratio (95% CI)
Block 1				
Age	.02	2.22	.14	1.02 (.99 - 1.05)
Gender	-.06	.03	.87	.94 (.45 - 1.96)
Race	.30	.1.04	.31	1.35 (.76 - 2.42)
Education	-.16	.24	.63	.85 (.45 - 1.62)
Injection drug use	-.24	.56	.46	.79 (.42 - 1.47)
Insurance status	-.03	.01	.94	.97 (.45 - 2.10)
Income status	.82	3.00	.08	2.27 (.90 - 5.75)
Block 2				
Taking antiretroviral medications	-.55	2.34	.13	.58 (.28 - 1.17)
Symptom intensity	.05	.46	.50	1.06 (.90 - 1.23)
Symptom bothersomeness	-.11	1.58	.21	.89 (.75 - 1.06)
Symptom affects daily life	.01	.02	.89	1.01 (.87 - 1.17)
-2 Log Likelihood	325.35			
Model Chi-square (df = 11)	12.47	(p = .33)		
Block 1 Chi-square (df = 7)	7.73	(p = .36)		
Block 2 Chi-square (df = 4)	4.75	(p = .31)		

§Unstandardized logistic regression coefficients.

* Level of significance: alpha = .05.

Table 22

Logistic Regression: Prediction of the Likelihood of Using Help Seeking as Self-Care Strategy (n = 297)

Predictor Variable	$b^{\S}$	Wald	*p*	Odds Ratio (95% CI)
Block 1				
Age	.03	3.27	.07	1.03 (.99 - 1.07)
Gender	.65	3.10	.08	1.91 (.93 - 3.92)
Race	1.74	18.23	.00	5.71 (2.57 - 12.70)
Education	.49	1.85	.17	1.63 (.81 - 3.28)
Injection drug use	.53	2.39	.12	1.70 (.87 - 3.32)
Insurance status	-.55	1.83	.18	.58 (.26 - 1.28)
Income status	.15	.11	.74	1.16 (.49 - 2.76)
Block 2				
Taking antiretroviral medications	.30	.66	.42	1.35 (.65 - 2.79)
Symptom intensity	-.02	.06	.81	.98 (.81 - 1.17)
Symptom bothersomeness	.03	.09	.77	1.03 (.85 - 1.25)
Symptom affects daily life	.02	.07	.79	1.02 (.87 - 1.21)
-2 Log Likelihood	246.06			
Model Chi-square (df = 11)	58.25	(p = .000)		
Block 1 Chi-square (df = 7)	57.22	(p = .000)		
Block 2 Chi-square (df = 4)	1.03	(p = .91)		

§Unstandardized logistic regression coefficients.
* Level of significance: alpha = .05.

Table 23

Logistic Regression: Prediction of the Likelihood of Using Exercise as Self-Care Strategy (n = 297)

Predictor Variable	b§	Wald	*p*	Odds Ratio (95% CI)
Block 1				
Age	.01	.16	.69	1.01 (.97 - 1.05)
Gender	-.02	.00	.97	.98 (.38 - 2.52)
Race	.58	2.11	.15	1.78 (.82 - 3.87)
Education	-.55	1.55	.21	.58 (.24 - 1.37)
Injection drug use	.45	1.24	.27	1.56 (.71 - 3.42)
Insurance status	-.13	.07	.79	.88 (.33 - 2.35)
Income status	.07	.02	.89	1.08 (.38 - 3.07)
Block 2				
Taking antiretroviral medications	.19	.19	.66	1.20 (.52 - 2.76)
Symptom intensity	-.05	.25	.62	.95 (.77 - 1.17)
Symptom bothersomeness	-.11	.79	.37	.90 (.71 - 1.14)
Symptom affects daily life	.07	.41	.52	1.07 (.87 - 1.31)
-2 Log Likelihood	213.13			
Model Chi-square (df = 11)	6.25	(p = .86)		
Block 1 Chi-square (df = 7)	4.32	(p = .74)		
Block 2 Chi-square (df = 4)	1.93	(p = .75)		

§Unstandardized logistic regression coefficients.
* Level of significance: alpha = .05.

Table 24

Logistic Regression: Prediction of the Likelihood of Using Spiritual Care as Self-Care Strategy (n = 297)

Predictor Variable	$b^{\S}$	Wald	*p*	Odds Ratio (95% CI)
Block 1				
Age	.01	.51	.48	1.01 (.98 - 1.06)
Gender	1.32	10.89	.00	3.76 (1.71 - 8.25)
Race	1.63	9.55	.00	5.09 (1.81 - 14.30)
Education	.28	.45	.50	1.33 (.58 - 3.06)
Injection drug use	.61	2.25	.13	1.84 (.83 - 4.06)
Insurance status	-.56	1.52	.22	.57 (.23 - 1.39)
Income status	-.89	3.79	.05	.41 (.17 - 1.01)
Block 2				
Taking antiretroviral medications	-.10	.05	.83	.90 (.36 - 2.25)
Symptom intensity	-.12	1.05	.31	.89 (.71 - 1.11)
Symptom bothersomeness	-.20	2.97	.08	1.22 (.97 - 1.53)
Symptom affects daily life	-.14	2.05	.15	.87 (.72 - 1.05)
-2 Log Likelihood	182.47			
Model Chi-square (df = 11)	59.60	(p = .000)		
Block 1 Chi-square (df = 7)	55.19	(p = .000)		
Block 2 Chi-square (df = 4)	4.40	(p = .35)		

§Unstandardized logistic regression coefficients.

* Level of significance: alpha = .05.

CHAPTER 5 DISCUSSION

Review of Findings

This chapter discusses the issues of generalizability, limitations, and findings of this study, along with the implications for nursing practice and future research. The results of this study are further compared and contrasted with prior HIV-related studies and knowledge about patients' self-care practice. Separate sections are devoted to the taxonomy of self-care strategies, information resources for self-care, predictors of self-care strategies and information technology in health care research.

This study used a nested data analysis approach to structure research questions and data analysis procedures. Phase one of the analysis used quantitative content analysis to develop inductively a scheme for categorizing HIV/AIDS symptom self-care strategies. Phase two of the analysis compared the proportions of self-care strategies across self-care information resources and symptoms; each completed survey based on one symptom was treated as the unit of analysis. Phase three of the analysis tested the predictive model of personal and disease characteristics for each type of self-care strategy use. Orem's self-care theory and Holzemer's Outcomes Model for Health Care Research were used to guide the selection of variables.

The category scheme includes eight types of self-care strategies: medications, complementary treatment, self-comforting, daily thoughts/ activities, changing diet, help seeking, exercise, and spiritual care. There are also four types of reported self-care information resources: self, personal network, community, and health care provider. There are significant differences in the proportions of self-care strategies that are used for different symptoms. People who completed the web-based surveys reported using less self-comforting, help seeking, and spiritual care strategies. They were also less likely to use personal networks and health care providers as resources of self-care information. The test models showed that racial difference is the leading predictor in using medications, self-comforting, help seeking, and spiritual care as self-care strategies.

Generalizability

Because the sample was recruited from many clinical sites, the study sample includes diverse groups of patients and can approximately represent the nature of the population of people living with HIV/AIDS. Although a convenient sampling method was used for sample recruitment, the sample distribution also approximates the national distribution in the United States. According to the US Center for Disease Control and Prevention (CDC), the race/ethnicity distribution of cumulative AIDS cases through June 2001 (n = 793,026) was: White 42.5%, Black 38.1%, Hispanic 18.3%, Asian/Pacific Islander 0.7%, American Indian/ Alaska Native 0.3%, and other 0.1%. Meanwhile, the gender distribution reported from the CDC was: Male 82.8%, and Female 17.2% (Center for Disease Control and Prevention, 2001b). The race and gender distributions in this study sample reveal a higher percentage of female subjects (22.0%) and a lower percentage of Black (35.4%) and Hispanic (12.5%) participants than does the comparative CDC sample. However, the study sample includes not only participants from the United States but also some subjects from other countries who were recruited in the study through the web site. This may contribute to the differences in sample distribution when comparing this data set to the CDC data.

Limitations

This study was a secondary analysis from a study with a multiple-site sample, so there are possible limitations to the design. To some degree, the variables of interest in secondary analysis are limited to those that had been included in the original study. When setting up the regression models, the predictors were also chosen from the existing variables in the original study. For that reason, the scope of selecting predictors did not go beyond these variables. However, in this study, new variables for self-care strategies and self-care information resources were created after careful categorization from content analysis and reliability testing. It was therefore possible to examine the uses of different types of self-care strategies and their relationships with other predictors. This approach enables the investigator to add new dimensions in the data set and propose research questions with new theoretical and analytical bases.

Content analysis was used to analyze the text/narrative data of self-care strategies and information resources on self-care. Processing data directly from the participants' own verbal descriptions is a common analytic technique. The advantages of using this method in research are that they enable the investigator to analyze open-ended questions and obtain details from the subjects' own words. On the other hand, some issues may arise during the coding process. A central idea of content analysis is the classification and compression of many words of the text into much fewer content categories. This classification process can be based either on the precise meaning of the words or words bearing similar connotations. Different categorizations can be generated from the same text, depending on the different strategies and criteria that the investigators use in the coding process. Therefore, the validity of the categories are important for maintaining the validity and reliability of the classifications (Weber, 1985). In this study, validity and reliability were achieved by assuring the content validity and inter-rater reliability of the classification for the self-care strategies on the one hand and the resources of self-care information on the other. As a result, the possible bias from the coding process was reduced.

Findings of This Study in the Context of Existing Research

The Taxonomy of Self-Care Strategies

This study's findings show the wide variety of strategies used by people living with HIV/AIDS for the self-care of their symptoms (medications, self-comforting, complementary treatments, daily thoughts/activities, changing diet, seeking help, spiritual care, and exercise). The eight categories of self-care strategies as identified by this study reveal that people living with HIV/AIDS seek not only the help of medications but also follow a wide array of other self-developed or self-sought non-pharmaceutical strategies to allay their symptoms. Medications account for only 23.5% of the total reported self-care strategies. This finding is consistent with studies that have theorized about the kinds of activities that people with health conditions would use strategically for the purpose of self-care (Barofsky, 1978; Dean, 1981).

There is a limited literature that explores self-care strategies among people with HIV disease. Several categories of self-care strategies were also identified in these studies. Lovejoy et al. (1991) summarized self-care strategies as reported from HIV-positive men as stress reduction, cognitive strategies, interpersonal relationships, nutrition intake, symptom surveillance, alternative therapies and hygiene (n = 162). Allan (1990) reported that the self-care activities of HIV-positive men included diet, exercise, stress reduction, life-style changes, and attitudinal adjustments (n = 11). Sowell (1997) described activities used by HIV-positive women such as special dietary and nutritional practices, choosing not to use medically prescribed therapies, spiritual reliance and rituals, staying active, cognitive strategies, self-education and adopting healthy life styles for their self-care (n = 27). The findings from this study are consistent with these previous studies in terms of identifying various non-pharmaceutical strategies used in self-care. The significant differences between this study and the previous ones is that the self-care strategies that were identified and described were used for alleviating symptoms and were not presented as general self-care practices. Medications, self-comforting, and help-seeking are the types of self-care strategies that have not been addressed in the previous literature on HIV/AIDS patients. In addition, this study included a larger and more diverse sample than the previous studies. The findings of this study reflect an improved validation of the self-reported self-care strategies used by people living HIV/AIDS.

In this study, the uses of self-care strategies were also compared among common HIV-related symptoms. The findings suggest that there are differences of proportions among self-care strategies, depending on the nature of different symptoms. Medications and changing diet were mostly used for diarrhea. On the other hand, strategies of a more self-developed or self-learning nature, such as self-comforting, daily thoughts/activities, help seeking, exercise, and spiritual care, were mostly used for relieving anxiety/fear. No study in the literature was found that compared self-care strategies among several types of HIV-related symptoms, and only a few studies reported self-care strategies for a specific kind of symptom. Henry et al. (1999) reported that hospitalized AIDS patients used dietary supplements, vitamins, and medications for diarrhea. This finding is similar to the strategies for HIV-related diarrhea that have been reported in this study.

Information Resources for Self-Care

The findings of this study demonstrate that people living with HIV/AIDS develop their symptom self-care strategies mostly from their own experiences, experiments, learning from family and friends, and community resources. Among the identified resources of self-care information, only 28% were from various kinds of health care providers like physicians, psychiatrists, and nutritionists. The remaining information resources were the self (34%), personal networks (19%), and communities (18%). As Freidson (1970) has suggested, people seek help through a network of lay referral systems that comprise family members or other selected authoritative lay persons as potential consultants, before they reach the professionals. These findings are also consistent with other studies (Lovejoy et al., 1992) that demonstrate how HIV positive patients use multiple sources in seeking self-care information. Health care providers are neither the sole or primary resources for this information seeking. In this study, patients reported relying significantly on self-experimentation and experience for dealing with symptoms.

In addition, this study demonstrates differences in the use of information resources, based on the categories of self-care strategies. The self was the most frequently used information source in most self-care strategies, with the exception of medication strategies, which are learned mostly from health care providers, and spiritual care strategies, which are mostly obtained from personal networks. No existing study in current HIV/AIDS literature has made similar comparisons. This study's findings help to reveal the information resources that HIV/AIDS patients use when seeking knowledge about self-care. It shows consistently, as earlier results have indicated, that people rely on themselves and those closed to them for non-traditional treatments and comforting strategies.

Information Technology in Health Care Research

The results of this study regarding the demographic characteristics of web-based subjects are consistent with other studies that make use of Internet web sites for distributing and completing health-related questionnaires. The findings demonstrate that the participants of web-based surveys, in comparison with participants in interview surveys, tend to be young, white, male, well-educated, non-users of injection drugs, and positively diagnosed with AIDS. Similar results were obtained in other studies that used web-based questionnaires and surveys: most of their respondents were white and more well-educated (Alexander & Trissel, 1996; Fawcett & Buhle, 1995; Soetikno et al., 1997). Kalishman et al. (2002) found that 51% (n = 116) of HIV/AIDS patients reported using the Internet at least once, and that the Internet users were significantly more likely to be better educated and have higher income. These findings suggest that conducting web-based surveys can benefit health care research in expanding geographical coverage and maintaining the anonymity of respondents, but the efficacy of the approach is still seriously limited, since Internet use has not penetrated the various ethnic groups and classes of society equally. Consequently, many HIV/AIDS patients simply do not have access to the Internet, and any web-based survey would not include their data.

This study also compared the use of self-care strategies and information resources among web-based and interview surveys. The results demonstrated that the web-based participants reported less use in help seeking strategy, spiritual care strategy, and personal network as resource. Besides the demographic distinction between web-based and interview participants, another possible explanation is that the personality characteristics of the people who can use the Internet comfortably might also contribute to the fact that they are less reliant on help from their social network for their HIV/AIDS care management. The popularity of the Internet may have already changed the ways that people become more self-reliant, since the process of using and conducting searches on the Internet requires being self-directed and self-motivated. Another possible explanation is that the social support structure differs due to the gender and ethnicity differences among web-site and interview participants. The larger proportion of male and White participants in the web-site sample may in fact use different resources to manage their symptoms in comparison with the female or non-White participants who were recruited mostly in the interview surveys.

Predictors of Self-Care Strategies

This study tested the contribution of personal characteristics and disease characteristics to the use of self-care strategy. The predictors included age, gender, race, education, injection drug use, insurance status, income status, whether the patient is taking antiretroviral mediations, symptom intensity, symptom bothersomeness, and the degree to which the symptom affects daily life. Among the eight types of self-care strategies, the predictive model explained the use of four self-care strategies: medications, self-comforting, help seeking, and spiritual care. Symptom intensity and race were found to be the most significant predictors for use of medications; race was the most significant predictor for self-comforting strategy and help seeking strategy; and gender and race were the most significant predictors for spiritual care strategy. People with higher symptom intensity were also more likely to use medications. People of color were more likely to use self-comforting, help seeking, and spiritual care strategies, but less likely to use medications, and women were more likely to use spiritual care strategies than men.

Medications

These results suggest that increased symptom intensity causes people to adopt strategies having more direct therapeutic effects, like medications, to alleviate symptoms. In addition, the tendency among people of color to adopt more self-developed strategies, like self-comforting, help seeking, and spiritual care, and the tendency of women to adopt more spiritual care strategies may be caused by discrepancies in the experiences and customs of dealing with health problems, as well as the different kinds of resources available to various cultural groups. The preference among people of color for self-care strategies over medications, as shown in the results of this study, may be the result of individual coping habits and experiences, inadequate resources from health care professionals, inadequate access to medications, or higher levels of psychosocial stress that would prompt the search for strategies such as spiritual care.

Using medications has been considered the traditional, orthodox approach for alleviating symptoms and discomfort. This study shows that symptom intensity significantly predicts the use of medications for self-care. The medications reported from this study included both prescribed and over-the-counter medications. Earlier studies have already pointed out that using over-the-counter or non-prescribed medications has been a common, daily self-care behavior for symptom control (Dean, 1981; Segall, 1990). Besides antiretroviral agents, Fogelman et al. (1994) reported that HIV/AIDS patients (n = 2,801) used concomitant drugs such as anti-infectives, analgesics, antipyretics, and vitamins. Other studies have reported that HIV patients use non-prescribed medications for sleep disturbance (Nokes, Chidekel, & Kendrew, 1999); they use both prescribed and non-prescribed medications for diarrhea (Henry et al., 1999) and pain (Holzemer et al., 1998). The tendency among people of color to use fewer medications was anticipated by Smith, Boyd, and Kirking (1999), who found that African-Americans were less likely to use nonprescription drugs, vitamins, and herbs, compared with non-Hispanic Whites. Similarly, Hispanics were less likely to report use of herbs or recreational drugs than non-Hispanic Whites.

Spiritual care

Spirituality has been documented as a coping resource for people living with chronic illnesses such as HIV. It has been viewed as a component of well-being by enabling movement from hopelessness to meaningfulness of life (Fryback & Reinert, 1999; O'Neill & Kenny, 1998). The outcome of this study showing that HIV positive women and people of color are more likely to use spiritual care activities for self-care is corroborated by earlier studies that have documented the use of spirituality among these groups. Women with HIV described the importance of spirituality in their dealing with the economic, physical, social and emotional challenges of everyday life while living with this life-threatening disease (Woodard & Richard, 2001). Another study using the focus group method (n = 45) concluded that the themes of spirituality used by HIV positive women included relationship with a supreme being, prayer and meditation, healing, peace, love, and religiosity (Guillory, Sowell, Moneyham, & Seals, 1997). A third study found that there was a significant positive relationship between hope and spiritual activities among HIV-infected African-American women (Phillips & Sowell, 2000). Coleman and Holzemer

(1999) also found that spiritual well-being was significantly related to the psychological well-being of HIV positive African Americans.

Help seeking

Help-seeking activities were found to be used more widely by non-White HIV infected patients in this study. The help-seeking strategies include talking to or seeking help from both health care professionals and persons who were not professional, such as peers and family. No recent study was found in existing HIV/AIDS literature that had also compared the differences in this type of behavior across different cultural groups. However, some early studies described the activities among HIV/AIDS positive gay men of help-seeking from either professional or non-professional resources. A study based on a sample of gay/bisexual African-American men (n = 316) showed that 36% of the sample reported seeking help out of their concerns about HIV high-risk sexual behaviors. Peers and professionals were the most widely sought sources of help. Furthermore, those who were HIV seropositive were more likely to seek help from professionals and peers (Peterson et al., 1995). Another study demonstrated that friends and primary sexual partners were the most frequently sources sought in dealing with death anxiety. In addition, men experiencing HIV symptoms were more likely than HIV-negative and asymptomatic men to use support from formal sources (medical, psychological) (Catania, Turner, Choi, & Coates, 1992).

Self-comforting

Whereas this study examines and compares self-comforting strategies (taking naps, reading books, crying, taking showers, watching TV, keeping busy, listening to music, rubbing legs, counting, etc.—actions intended to provide comfort and temporarily relieve symptoms) among different ethnic groups and points out that such activities are more likely to be used by non-White HIV-positive patients, no similar study has been found that does the same. This may be due to non-White HIV patients' preference for self-developed activities or use of resources available at home. On the other hand, this difference may also be due to underreporting by White HIV patients who are less likely to consider these activities as self-care strategies.

Complementary treatment

The predictive model did not explain the use of complementary treatments, daily thoughts/activities, changing diet, and exercise as self-care strategies. Other variables may contribute to their use. HIV/AIDS patients are increasingly using complementary and alternative therapies (CAM) to alleviate symptoms. Sparber et al. (2000) reported that 91% of the HIV/AIDS patients (n = 100) had used at least one CAM therapy. Bates et al. (1996) investigated factors associated with the self-reported use of complementary therapies among HIV/AIDS patients living in the southern United States and found that the percentage of complementary therapy use was 31%. That study also found that people who used complementary therapy were more likely to be white, female, a high school graduate, and acquainted with another complementary therapy user. The present study, however, found no predictive relationship from personal characteristics and disease characteristics, perhaps because of the increasingly popular use of complementary treatments among all groups of HIV/AIDS patients and the increasing number of non-White patients. Thus, personal and socioeconomic factors may not be able significantly to predict differences in complementary treatment use across genders and ethnic groups.

Changing diet and Exercise

Changing diet and exercise are also common strategies for managing most symptoms, but the predictors selected in the regression model that was used in this study do not show correlation with decisions by HIV/AIDS patients as to whether or not they use these self-care strategies. However, the comparisons across symptoms from the present study suggests that exercise is used most frequently for to alleviate anxiety/fear, and that changing diet is used mostly for alleviating diarrhea. In comparison, Collins et al. (2001) reported that people with HIV made changes in health-promoting behaviors (diet, exercise, smoking, and substance use) after they tested positive for HIV. The desire to get involved in one's HIV care, seek information, and cope positively with the disease were also correlated with these changes. According to other studies in this area, the adoption of these strategies may also depend more upon the type and nature of the symptoms. For example, exercise has been used for symptoms like wasting, hyperlipidemia, or fatigue (Arey & Beal, 2002; Smith et al., 2001), and changing diet or foods has been reported helpful for gastrointestinal symptoms (nausea, diarrhea) (Henry et al., 1999; Kim, Spiegelman, Rimm, & Gorbach, 2001).

Daily thoughts/activities

The present study found that the predictive model does not explain usage of the "daily thoughts/activities" category, in which patients changed their daily/social routines or their thoughts about the disease and symptoms. Other studies have also shown that people living with HIV/AIDS experience significant impacts on the quality of life not only because of the ailment itself but also because of its social stigma as a life-threatening disease. Like those who suffer from other chronic illnesses, HIV/AIDS patients adjust their daily and social schedules and change their thoughts about the disease as part of the process by which they cope and adopt the illness into their own lives (Holzemer & Wilson, 1995). The lack of predictive factors in this type of self-care strategy may suggest that it is a universal strategy among HIV/AIDS patients in responding to their symptoms.

Implications for Nursing Practice

Because people living with HIV/AIDS try a variety of strategies for symptom self-care, and medications are only one of them, health care providers should pay more attention to evaluating these self-care symptom management strategies and provide HIV/AIDS patients more options for managing the multidimensional nature of their symptoms, which affect not only physical but also psychological and spiritual well-being. These symptom management strategies can be tailored according to the nature of the symptoms. Furthermore, this study's findings suggest that these self-care strategies may be the ones that patients feel comfortable using for symptom management. However, the reporting on these strategies may have also been affected by a lack of other, more effective strategies, which made it necessary for patients to try and develop other approaches on their own. Therefore, clinicians need to be aware of the self-care practices that patients use when they assess patients' symptoms. This study's findings also suggest that patients learn their self-care strategies mostly on their own or through their own social networks. Since most HIV/AIDS patients use themselves as the resources of self-care information, enhancing patients' own knowledge of symptom management is also important. It is then beneficial to develop innovative and effective channels for the publics to access relevant self-care information. For the clinicians, besides enhancing their role in coaching symptom management, they could also use community, family, and partner as education channels on the behalf of patients to improve the patients' self-care efficiency.

Recommendations for Future Research

The categorization of symptom self-care strategies demonstrates the diversity of available strategies for alleviating symptom discomforts. Patients with chronic illnesses try to cope and live with the symptoms by contemplating and taking actions to manage the symptoms. Further research could address the effectiveness of these strategies. The strategies that patients choose might not be the most effective ones, since they may apply these strategies incorrectly, without proper knowledge and skills.

The test of the predictive model shows that personal characteristics and disease characteristics can explain half of the eight self-care strategies. Racial difference was the most important predictor in all the strategies explained in this study. Future research could focus on other health-related behaviors and their outcomes among HIV/AIDS patients with different cultural and socioeconomic backgrounds. In addition, other variables such as, perhaps, coping style and health status may be tested for those self-care strategies that could not be explained from the variables selected in this study. Self-care is an important health behavior for people with chronic illness, since it is the means by which they maintain their well-being and health outcomes. For these reasons, it must be taken into account in any discussion of effective HIV/AIDS care management.

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