Linking HIV/AIDS Clients’ Self-Care With Outcomes

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The self-care practice of HIV/AIDS patients has become an important topic to help HIV/AIDS patients maintain their maximum level of well-being in chronic illness management. This article presents a self-care outcomes model that is applicable to HIV/AIDS nursing practice and research, and it identifies attributes and outcomes related to HIV/AIDS patients’ self-care. The self-care outcomes model was developed based on the Outcomes Model for Health Care Research and literature review. Key variables related to HIV/AIDS self-care were summarized and discussed based on nine dimensions: client inputs, client processes, client outcomes, provider inputs, provider processes, provider outcomes, setting inputs, setting processes, and setting outcomes. This article reveals that self-care in HIV/AIDS is complex and may be influenced by many factors relating to individual, family, and health care system. More research with advanced multivariate statistical models and randomized controlled trial design will help determine the effectiveness of self-care strategies and interventions.

Key words: HIV/AIDS, self-care, Outcomes Model

Patient self-care practices are important components in care management for chronic illnesses. Infection with human immunodeficiency virus (HIV) has become a long-term chronic disease that presents a continuing cycle of monitoring and managing health problems that demand management (Reiter, 2000). As with most chronic illnesses, much of the care for HIV infection is managed in outpatient and home settings. As a result, people living with HIV disease are challenged 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. Understanding self-care by people living with HIV has the potential to significantly enhance HIV disease management.

This article presents a self-care outcomes model derived from the Outcomes Model for Health Care Research (Holzemer, 1994). Attributes and outcomes that are relevant to HIV/AIDS self-care were identified from the literature and organized based on the dimensions of the Outcomes Model for Health Care Research. Literature from 1985 to 2002 was found by searching in MEDLINE, CINAHL, and AIDSnet databases for empirical studies in HIV/AIDS self-care. Terms like self-care, HIV, and AIDS were used to retrieve studies and key findings related to self-care in HIV/AIDS. Common concepts relevant to self-care that had been studied among patients with other chronic illness were also included to explore applicability to HIV research. The variables selected are not exhaustive.

The Outcomes Model for Health Care Research is based on the work by Donabedian (1982), and provides a model for synthesizing related concepts and identifying gaps in understanding the relationships among patient characteristics, self-care, setting, provider interventions, and outcomes. The Outcomes Model has been used as a framework to assist in identifying health-related outcomes within primary health care (Holzemer, 1994) and medical informatics.

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The Outcomes Model for Health Care Research is a three-by-three matrix scheme that helps organize variables of interest. The model focuses on inputs, processes, and outcomes for evaluating quality of care according to the dimensions of client, provider, and setting. Client can include the patient, family caregiver, or community. The term provider can refer to different types of health care professionals. Setting can be a hospital, outpatient clinic, home, or wherever the patient receives health care. A time dimension is incorporated in the horizontal axis of inputs, processes, and outcomes that includes pre-event, event, and postevent. When the model is used for designing research, the inputs and processes can be deemed as covariates or exogenous variables, independent variables, or interventions. The outcomes are often the dependent variables.

### Defining Self-Care

Scholars in nursing and other disciplines had proposed definitions related to patient self-care. Levin et al. (Levin, Katz, & Holst, 1979; Levin & Idler, 1983) defined self-care as a process whereby a layperson can function effectively on his or her own behalf in health promotion, disease prevention and detection, and treatment at the level of the primary health resource in the health care system. Dean (1981) suggested that several types of activities, including health maintenance, utilization of preventive services, symptom evaluation, and interaction with health care professionals, are self-care activities. 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).

Orem also postulated self-care as a multiple dimensional construct including self-care agency, self-care requisite, and self-care deficit. These existing definitions suggest that self-care responds to all aspects of health issues from prevention to maintenance, and they are helpful to guide in understanding the scope of self-care. However, these current definitions were initially developed for general health and other chronic conditions and not specifically for HIV/AIDS.

In this article, self-care is considered as a multidimensional concept that refers to the knowledge, attitudes, and behaviors that clients develop, nurture, or perform to manage a health problem or to enhance a healthy attribute. Knowledge in HIV/AIDS self-care includes the information HIV/AIDS patients have for their self-care practice (Lovejoy, Moran, & Paul, 1988). Attitude in HIV/AIDS self-care can include patients’ perceptions of the burden (Anastasio, McMahan, Daniels, Nicholas, & Paul-Simon, 1995) and barriers (Leenerts, 1998) in their own self-care. Behaviors of HIV/AIDS self-care refer to the self-care strategies that patients perform for their symptom management (Henry, Holzemer, Weaver, & Stotts, 1999). In addition to the dimensions in the concept of self-care, the scope of self-care practice in HIV/AIDS can include two levels: generic self-care for health maintenance (e.g., nutrition, exercise, stress reduction) (Sowell et al., 1997) and specific self-care related to managing HIV treatment and care (e.g., symptom management, medication adherence, engagement with care) (Holzemer et al., 1999).

### Self-Care and Outcomes

The variables relevant to HIV/AIDS self-care are summarized in the self-care outcomes model (Table 1). Current understanding and gaps of knowledge in the relations among attributes, self-care, and outcomes are discussed based on each dimension proposed in the model.

#### Client Input

Client inputs are characteristics, strengths, and problems related to the person with HIV/AIDS. Five categories of inputs related to the client include demographics, personality, risk behavior, socioeconomic factors, and severity of illness. Sociodemographic characteristics have been investigated as correlates of health outcomes in most health-care outcome studies. Orem proposed in her self-care theory that several basic conditioning factors can influence a person’s ability and the way they do self-care (Orem, 2001). Age and gender are examples of personal characteristics that play a role in determining self-care practice. Studies in other chronic illness populations have consistently shown some correlations. For instance, Johnson, Kincade, Bernard, Busby-Whitehead, and
DeFriese (2001) reported that elderly women use more types of self-care activities to manage urinary incontinence than do elderly men.

Few studies have explored the correlations among client inputs and self-care in people with HIV/AIDS. The potential for these relationships can be found in a few studies that described the meaning of self-care in HIV/AIDS patients with certain demographic characteristics. Patients’ self-care activities were explored in HIV seropositive women (Sowell et al., 1997) and gay men (Allan, 1990). However, it is unclear in the literature whether self-care activities are significantly different among HIV patients by gender. Other demographic characteristics related to self-care could also include external locus of control (Lovejoy, Paul, Freeman, & Christianson, 1991), economic and social problems encountered by patients (Banksberg et al., 2000; Leenerts, 1998), and level of health literacy (Kalichman, Ramachandran, & Catz, 1999).

Symptom management is a significant problem for people with HIV/AIDS, especially because the current antiretroviral medications exacerbate the problem of symptom management in HIV/AIDS care (Holzemer, 2002; Hurley & Ungvarski, 1994). Studies show that people living with HIV/AIDS experience multiple symptoms, both physiological (fever, diarrhea, headache, shortness of breath, fatigue) (Mathews et al., 2000) and psychological (anxiety, depression, fear) (Vogl et al., 1999). The number of physical symptoms experienced by patients with HIV was found to be positively associated with depression and the tendency to engage in unhealthy self-care behaviors such as increased consumption of junk food or use of recreational drugs (Valente, Saunders, & Uman, 1993).

The stage of illness also affects how patients perceive and cope with their health condition. Being aware of the diagnosis may trigger a change in self-care activities. In a study by Lovejoy et al. (1988), it was found that the use of self-care activities increased in a group of gay and bisexual patients after being informed of the AIDS diagnosis; the use of recreational drugs and stimulants decreased after the diagnosis. In a second study, these authors reported that 35 of 81 self-care behaviors increased after the patients became aware of their HIV-seropositive status (Lovejoy et al., 1991). Gerbert, Love, Caspers, Linkins, & Burack (1999) also found that HIV-seropositive patients became more involved with their health care when they knew of the HIV diagnosis, started to experience HIV-related symptoms, and started drug treatment intervention.

The availability of social support has been shown to be related to better health outcomes in gay men with HIV/AIDS (Hall, 1999), higher quality of life in patients with HIV (Swindells et al., 1999), lower level of distress in women with HIV (Hudson, Lee, Miramontes, & Portillo, 2001), and delay in seeking care by women with HIV (Williams, Shahryarinejad,

### Table 1. Outcomes Model for HIV/AIDS Patient Self-Care

<table>
<thead>
<tr>
<th>Input</th>
<th>Processes</th>
<th>Outcomes</th>
</tr>
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<tbody>
<tr>
<td>Client</td>
<td>Demographic: age, gender, culture, literacy, ethnicity;</td>
<td>Patient self-care: self-care strategy, self-care agency, self-care burden, self-care deficit; Engagement with health care providers; Adherence; Self-management program; Health education/consumer health information; Engagement with client; Provider-patient relationship</td>
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<td></td>
<td>Socioeconomic: social support, income, insurance, housing, environmental exposure, employment; Severity of illness: symptoms, AIDS diagnosis, HIV-positive status; Personality: self-efficacy, locus of control; Risk behavior: injection drug use, alcohol, sexual behavior, risky behavior</td>
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<td></td>
<td>Type of case manager: lay, social worker, nurse; Type of primary care provider: physician, nurse practitioner; Education: specialty training; Experience</td>
<td>Self-management program; Case management; Use of HIV treatment guidelines; Service availability: drug access, hospice care, availability of case management</td>
</tr>
<tr>
<td>Setting</td>
<td>Urban/rural area, hospital/community/private practice, health technology; Availability of specialized AIDS care; Guidelines of policies and procedures; Policy programs: Medicaid, Medicare, Ryan White, private plans</td>
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Andrews, & Alcabes, 1997). These findings suggest that social support is one of the client input factors that appears to influence patients’ abilities to perform self-care, but no studies have been found that directly explored this possible relationship. Unknown in these studies is the potential impact of the availability of Medicaid and Ryan White funds or AIDS Drug Assistance Program services on enhancing social support.

Self-efficacy has been discussed theoretically as a predisposing factor to self-care in some health behavior theories such as Bandura’s Self-Efficacy Theory (Bandura, 1997). Studies have examined the level of self-efficacy of HIV-positive patients in relation to preventive behaviors such as practicing safe sex (Adih & Alexander, 1999; Kalichman & Nachimson, 1999) and medication adherence (Gifford et al., 2000). Whether self-efficacy is associated with self-care practices for HIV/AIDS-related conditions needs further research.

An individual’s self-care practices may also vary because of different cultural and ethnic health-related practices. Activities such as religious participation may be part of the self-care activities that patients with HIV disease or other chronic conditions use to help relieve discomfort and distress. Coleman and Holzemer (1999) found high spirituality among a sample of African American men with HIV/AIDS. In summary, there is little research on the correlates of client inputs with self-care activities that can inform clinical practice.

**Client Processes**

HIV patients’ self-care is considered as the dimension of client processes in this outcomes model. Most of the current literature in HIV/AIDS self-care relates to the self-care activities or strategies used by patients with HIV/AIDS. Very little research investigates other dimensions of self-care such as self-care agency, self-care efficacy, or self-care deficit. Studies have shown that HIV/AIDS patients undertake various types of self-care activities such as diet (Allan, 1990; Lovejoy et al., 1988), exercise (Allan, 1990; Sowell et al., 1997), use of complementary therapies (Lovejoy et al., 1988; MacIntyre & Holzemer, 1997), changing lifestyles (Allan, 1990; Sowell et al., 1997), use of stress-reduction techniques (Allan, 1990; Barroso, 1995; Lovejoy et al., 1988), self-education, and monitoring symptoms (Lovejoy et al., 1988; Sowell et al., 1997).

Self-care symptom management strategies have also been explored. Henry et al. (1999) reported that hospitalized AIDS patients use a variety of self-care activities to manage diarrhea such as taking dietary supplements, vitamins, and medications. Categories of patient self-reported self-care activities in managing major symptoms have also been reported for some frequently occurring HIV-related symptoms. Holzemer et al. (2001) reported that over-the-counter medications, activities, food supplements, dietary changes, and changing thoughts were the self-care strategies used for controlling diarrhea. Talking to others, keeping active, taking prescribed medications, using recreational drugs, using avoidance behaviors, and using complementary therapies were reported self-care strategies for reducing anxiety and fear (Kemppainen et al., 2003). Complementary therapies, medications, exercise, rest, and substance use were used as self-care strategies for peripheral neuropathy (Nicholas et al., 2002). Eller et al. (2001) reported that distraction, talking, using antidepressants, alternative therapies, denial, and use of drugs and alcohol were described as self-care strategies for reducing depression; rest and sleep, exercise, vitamins and supplements, and stress management were self-care strategies for reducing fatigue (Corless et al., 2002).

Besides understanding what patients do for self-care, investigating the patient’s ability and confidence to do self-care is also important for HIV/AIDS research and practice. However, little research investigated other dimensions of self-care in HIV/AIDS literature. Anastasio and colleagues (1995) examined the burden related to self-care practices in women with HIV and found that home treatments, obtaining resources, and eating a special diet were examples of self-care tasks that the participants felt were a burden. Self-care agency and self-care deficit have not been examined in persons with HIV/AIDS, although these concepts have been studied in other chronically ill patients.

**Client Outcomes**

A wide spectrum of patient outcomes can be evaluated in relation to self-care for HIV-related conditions.
Concepts like symptom status, quality of life, adherence, and access to care are examples of patient outcomes that seem appropriately associated with self-care practices of HIV/AIDS patients. Few studies, however, have documented the effects of self-care on patient outcomes. The number of categories of self-care management activities was found to be significantly associated with general health perceptions of HIV-positive patients with diarrhea (Henry et al., 1999). It has also been shown that women with HIV/AIDS who practiced health-promoting self-care behaviors report better physical and mental health and better overall quality of life (Gielen, McDonnell, Wu, O’Campo, & Faden, 2001). How self-care of HIV/AIDS patients is correlated with other patient outcomes requires more investigation.

Biomedical markers have also been examined as patient outcomes to determine the effectiveness of self-care interventions. Examples from studies of patients with other chronic illnesses have shown the effects of self-care or self-care-related intervention on biomedical markers such as glycohemoglobin levels in diabetes patients (Day, Bodmer, & Dunn, 1996). Laboratory markers like CD4 count and viral load have been considered essential indicators for HIV disease progression, initiation of antiretroviral therapy, and level of medication adherence (Gifford et al., 2000; Paterson et al., 2000). Patients’ better self-care adherence to medication has been shown to be directly related to a higher CD4 count and a lower viral load level and rebound (Gross, Bilker, Friedman, & Strom, 2001; Le Moing et al., 2002).

The review on HIV/AIDS self-care research in the dimensions of client inputs, client processes, and client outcomes reveals consistently that people living with HIV/AIDS utilized several types of self-care strategies for maintaining health and managing symptoms in several descriptive studies. However, whether these strategies are effective is inconclusive in the literature. Additionally, because most studies used qualitative and descriptive approaches to investigate HIV patients’ self-care, only a few instruments were developed and used to measure different dimensions of self-care in HIV/AIDS research (Anastasio et al., 1995; Lovejoy et al., 1991; Valente et al., 1993). Another limitation from the existing literature is that most of the studies had relatively homogeneous samples such as gay men (Lovejoy et al., 1991) or women (Leenerts, 1998; Sowell et al., 1997). As the demography of HIV/AIDS gradually changes to a more diverse population, including a more heterogeneous sample will help compare whether self-care practice differs among subgroups of HIV/AIDS patients.

The review in current literature also suggests unclear associations between which factors influence HIV/AIDS patients’ self-care practices and whether self-care affects possible outcomes, such as improving quality of life and controlling HIV disease progression. These areas can be further explored in HIV/AIDS research.

**Provider Inputs**

Provider input variables such as type of case manager (lay, social worker, or nurse) and type of primary care provider (physician or nurse practitioner) may be related to facilitating clients’ self-care behaviors. No study was found that directly examined the association between provider characteristics and the self-care practices of the HIV/AIDS patient. Aiken et al. (1993) reported that HIV-positive patients who received care from nurse practitioners reported significantly fewer problems with their care than those who received care from physicians, but self-care strategies were not addressed. Level of provider education, specialization training, and experience may also have an impact on clients’ self-care. Kemppainen et al. (1992) found that nurses with BSN or MSN education employed in hospitals with low and moderate prevalence of AIDS were the most willing to provide AIDS patient care. The type of provider has been related to outcomes but not to self-care practices.

**Provider Processes**

Provider processes can include interventions designed to support self-care and improve quality of life. Interventions are primarily educational and focus on enhancing knowledge, supporting or changing attitudes, and learning or improving skills. Additionally, engagement and relationship between patients and providers would also affect self-care.

Very few studies have documented the effects of educational interventions on HIV/AIDS clients’ self-
care practices. For example, health education has been shown to improve self-efficacy for controlling symptoms and symptom status in a randomized controlled trial of symptomatic HIV/AIDS patients (Gifford, Laurent, Gonzales, Chesney, & Lorig, 1998). Self-management training that focused on psycho-educational coping techniques positively affected mood, coping styles, and health attitudes (Inouye, Flannelly, & Flannelly, 2001). Like most chronic illnesses, managing HIV/AIDS-related treatment and health care requires long-term partnerships between patients and health care professionals. Findings of an investigation revealed that HIV patients who were more engaged with their health care providers had higher adherence to their medication regimen and provider advice (Bakken et al., 2000). The relationships between providers and patients also influence the health information given to patients and their willingness to participate in their care. One study suggested that HIV-infected patients increase their participation in self-care and collaboration with care providers when there is a caring relationship with the care provider (Gerbert et al., 1999).

Provider Outcomes

Provider outcomes have not been major outcomes when direct effects of health care interventions are described. However, provider outcomes such as burden of care may have indirect or direct influences on patient outcomes (e.g., medication adherence). Whether patients with HIV can perform self-care appropriately may also affect providers’ outcomes such as the willingness to care, burden of care, and satisfaction.

The review of current literature in the dimensions of provider inputs, provider processes, and provider outcomes showed that the effects of provider-related variables on HIV patients’ self-care had largely been unexplored. Particularly, the interventions to promote and assist HIV patients in their self-care still need further development.

Setting Inputs

Several characteristics of health care systems may contribute to patient self-care because of the impact on availability for patient care resources. Variation in health insurance, availability of specialty care, or geographical differences between urban and rural areas are factors that may contribute to resource availability and for self-care practice. Aiken, Sloane, Lake, Sochalski, and Weber (1999) reported that hospitalized patients who received care in dedicated AIDS units and magnet hospitals, which were known to provide primary nursing, end-of-life care counseling, and discharge planning, had lower mortality and better satisfaction with care. Computer technology has also shown its potential benefit as a health education mechanism in enhancing self-care. Although no clear conclusions were found in the effects of structured, computerized HIV-prevention programs on patient self-care (Brennan & Ripich, 1994), benefits from information technology may exist, such as the potential to disseminate health education in a more timely manner. As the Internet becomes more available and user-friendly, the HIV/AIDS patient education information will be more accessible. However, given the literature on the digital divide, this technology may not be readily available to vulnerable or poor communities.

Setting Processes

Current health care delivery systems have aimed at expecting patients to manage their long-term illness through self-care at home and on an outpatient basis. The variations in health care delivery processes may have linkage with patients’ achievement of appropriate self-care (Henry & Holzemer, 1997). Case management is one of the setting processes that has a direct and indirect effect on patient health status or self-care. Case management is a health care delivery process to coordinate and provide comprehensive care. It is implemented to facilitate community-based care for HIV/AIDS patients. Wright, Henry, Holzemer, and Falknor (1993) documented that a wide variety of nursing skills were used by nurse case managers to provide case management services to persons with AIDS and AIDS-related complex. Case management is associated with fewer unmet needs and higher use of medications in patients with HIV (Katz et al., 2001) and less vertical transmission in infants (Havens et al., 1997). However, the association between current case management programs and the improvement in HIV/
AIDS patients’ daily lives (like quality of life, functional status, or self-care) needs further exploration.

Setting Outcomes

Self-care has been promoted as an effort to help decrease unnecessary health care costs and usage and to allow patients and caregivers to take better care of themselves at home and in the community. Studies in other clinical populations have shown decreased health care costs and utilization of services after patients were given interventions to enhance their self-care practices (Vickery, Golaszewski, Wright, & Kalmer, 1988). Yet no study was found that examined HIV patient’s self-care on system-level outcomes.

The review on the literature in the dimensions of setting inputs, setting processes, and setting outcomes indicates that characteristics of HIV/AIDS-patient care settings and delivery have effects on setting outcomes such as health care costs and service utilization. However, it is unknown whether the characteristics of a health care system have impacts on HIV/AIDS patients’ self-care and the associated patient outcomes.

Implications

The review of current literature demonstrates the research potential pertaining to self-care aimed at improving quality of life and reducing health care costs in the HIV/AIDS population. The self-care outcomes model presented in this article can serve as a platform for advancing the research in HIV/AIDS self-care. For example, the variables identified in the model help provide concepts and propositions for the development of research questions and hypotheses. The model can be used to determine the covariates and direct and indirect relationships among selected variables of interest related to self-care in HIV/AIDS research. Some hypothesized relationships among dimensions of the model are shown in Figure 1, which indicates correlations and potential causal relationships between variables that can be tested by researchers. The researchers can select their interested dimensions and test the correlations and causality to explore the effect of one dimension on the other.

Besides identifying possible factors and outcomes associated with self-care in HIV/AIDS patients, future research can include design of advanced multivariate
statistical techniques to analyze relationships between variables and to validate the self-care model. Randomized controlled trial designs can also help testing the effectiveness of self-care strategies and interventions for improving HIV/AIDS patients’ self-care practices. Obtaining the evidence of the effectiveness of these self-care strategies can provide HIV/AIDS patients with more options in symptom management and quality of life improvement. In addition to expanding research designs in HIV/AIDS self-care research, psychometric studies in HIV/AIDS self-care measurement are also needed to enhance the study validity. Up to now, few instruments have been developed and validated for measuring different aspects of self-care for people living with HIV/AIDS. More effort should be devoted to develop and test measurement instruments that are specific to HIV/AIDS self-care.

Research using this model may affect clinical care in several aspects. First, clinicians can use the research results to identify the HIV/AIDS patients who potentially can not perform effective self-care. Furthermore, because both setting and provider processes could also affect the self-care outcomes, self-care interventions could be developed by focusing not only on patient behavioral change but on improvement in providers’ commitment and health care setting to facilitate self-care practice. Last, the multidimensionality of self-care raised in the model enhances the ability to think about HIV/AIDS self-care in an integrative perspective. This can help in redesigning more comprehensive interventions aimed at assisting people with HIV/AIDS to manage the illness through the complex health care delivery system.

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References


physicians can help HIV-seropositive patients become more involved in their healthcare. AIDS Patient Care and STDs, 13(1), 20-39.


