Feasibility Testing of a Web-Based Symptom Self-Management System for Persons Living With HIV

Rebecca Schnall, RN, PhD
Dean Wantland, RN, PhD
Olivia Velez, RN, PhD
Kenrick Cato, RN, MPhil
Haomiao Jia, PhD

The purpose of this study was to explore the feasibility of using a Web-based tool to provide tailored symptom management strategies for persons living with HIV (PLWH) and to estimate the effect size of the tool for future studies. Testing the components of the Web-based system was done by incorporating a repeated-measures design measuring the outcomes of symptom frequency and intensity, use of symptom management strategies, and engagement with health care providers. We recruited 42 PLWH; participants were enrolled in the study for 12 weeks and were asked to use the system and complete the questionnaires every 2 weeks. Our results showed that participants who used the strategies were more likely to have a decrease in symptom frequency and intensity. Findings from this feasibility study provide preliminary evidence for the use of a Web-based HIV symptom management tool with self-management strategies for individuals living with HIV infection.

(Journal of the Association of Nurses in AIDS Care, 25, *364-371*) *Copyright © 2014 Association of Nurses in AIDS Care*

Key words: *persons living with HIV, symptom frequency, symptom intensity, Web-based tools*

In the United States, an estimated 1.1 million people are living with HIV, due in part to successful medications to treat the disease. As a result, HIV has evolved from an acute illness to a chronic illness, and may lead to a number of physiological and psychological symptoms that potentially impact the lives of people living with HIV (PLWH; Centers for Disease Control and Prevention, 2009). Moreover, many HIV-related symptoms frequently go unrecognized by health care providers; they are often underreported by patients and are often undertreated (Hughes, 2004). Patients' symptom experiences and symptom management are strongly related to HIV disease progression and clinical factors (Spirig, Moody, Battegay, & De Geest, 2005). For instance, the prevalence of individual signs and symptoms, as well as the intensity of the symptoms, influences patients' decisions to seek care. Symptoms have also contributed to reduced adherence to medications, which increases the likelihood of resistance to medication regimens and

Rebecca Schnall, RN, PhD, is an Assistant Professor, Columbia University School of Nursing, New York, New York, USA. Dean Wantland, RN, PhD, is an Assistant Professor, Rutgers, The State University of New Jersey, College of Nursing, Newark, New Jersey, USA. Olivia Velez, RN, PhD, is a Postdoctoral Fellow, Columbia University Department of Biomedical Informatics, New York, New York, USA. Kenrick Cato, RN, MPhil, is a PhD Candidate, Columbia University School of Nursing, New York, New York, USA. Haomiao Jia, PhD, is an Associate Professor of Clinical Biostatistics (in Nursing), Columbia University School of Nursing and School of Public Health, New York, New York, USA.

JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE, Vol. 25, No. 4, July/August 2014, 364-371
http://dx.doi.org/10.1016/j.jana.2013.09.002

exacerbation of symptoms (Siegel, Schrimshaw, & Dean, 1999). These factors may also reduce a person's quality of life (Lorenz, Cunningham, Spritzer, & Hays, 2006).

Much work has documented the use and relevance of various symptom management strategies for PLWH. This work includes fatigue (Corless et al., 2002), neuropathy (Nicholas et al., 2007), anxiety (Kemppainen et al., 2006), body changes associated with lipodystrophy (Nicholas, Kirksey, Corless, & Kemppainen, 2005), depression (Eller et al., 2005), and quality of life (Holzemer, Hudson, Kirksey, Hamilton, & Bakken, 2001). In a review of self-management of chronic illness, investigators reported that patient education and skills for self-management were both physically and psychologically beneficial (Coster & Norman, 2009).

While much work has documented the success of paper-based tools for symptom management, Web-based behavior change interventions offer an innovative strategy for symptom self-management. Information technology makes tailored communication possible by allowing for individual-specific information to be provided to each patient (Kreuter, Oswald, Bull, & Clark, 2000). Behavior change interventions can be effectively communicated by Web-based applications, and the interventions are at least as effective as traditional face-to-face and paper-based behavior change interventions (Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004). The purpose of our study was to explore the feasibility of using a Web-based tool to provide tailored symptom management strategies for PLWH and to estimate the effect size of the tool for future studies.

Methods

Study Design

We conducted a repeated-measures study to test the components of the new Web-based system on symptom frequency and intensity, use of symptom management strategies, and engagement with health care providers. We hypothesized that after exposure to the system for 12 weeks, there would be a decrease in symptom intensity and frequency; these were our primary outcomes. In addition, for secondary outcomes we hypothesized that after use of the system during the study period, there would be an improvement in (a) patient perceptions about engaging with their health care providers, (b) adherence, and (c) quality-of-life measures.

Description of the System

We built a Web-based symptom management tool for PLWH based on a symptom management manual validated by researchers at the University of California at San Francisco (UCSF) School of Nursing. The paper-based manual was tested in a randomized controlled trial to determine how well nurses using the manual could assess the symptom frequency and intensity for 775 PLWH for 3 months. Findings from the study showed improved helpfulness rating scores in participants who used the symptom management manual and a greater significant reduction in symptom intensity scores compared to the control group (Wantland et al., 2008).

Using the paper based-manual, which included strategies for 21 symptoms, we developed and iteratively refined a Web-based Symptom Self-Management tool for PLWH (UCSF, 2004). Due to funding constraints, the Web-based system provided tailored strategies for only six symptoms: (a) depression, (b) anxiety, (c) fatigue, (d) diarrhea, (e) neuropathy, and (f) nausea. To develop the system, we first did usability testing through a heuristic evaluation with five experts in human computer interaction (Schnall et al., 2011). Following that process, we conducted end-user usability testing with PLWH. Findings from the usability testing were used to refine the user interface and functionality of the system. The goal of the usability testing was not to refine the content of the symptom management strategies. Based on the feedback from the usability testing, we refined the system and launched the Web-based tool for a 12-week feasibility study to obtain effect size estimates on the change in symptom frequency and intensity.

The system was designed so that once users logged in, they were guided by an avatar through a series of questions ascertaining the nature and severity of their symptoms (Figure 1). Once the evaluation was completed, the avatar would recommend self-management strategies for managing specific symptoms, including anything from taking a nap to changing