



Meaning of Care for Terminally Ill HIV-infected Patients by HIV-infected Peer Caregivers in a Simulation-based Training Program in South Korea

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The purpose of this study was to develop a simulation-based training program for people living with HIV (PLWH) as peer caregivers who would take care of terminally ill, HIV-infected patients. We used qualitative research methods and standardized patients to explore the meaning of caring for patients as peer caregivers. Study participants included 32 patients registered as PLWH at the South Korea Federation for HIV/AIDS. The meanings of peer caregiving were categorized into four dimensions: physical, psychological, relational, and economic. Our study had benefits in knowledge acquisition for caregivers as well as care recipients, empathy with HIV-infected care recipients, improvement in self-esteem and social participation, and financial self-sufficiency to enable independent living for caregivers. The simulation training program for PLWH peer caregivers for terminally ill HIV-infected patients demonstrated value, for both PLWH caregivers and terminally ill HIV-infected patients in South Korea, to improve the quality of care.

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When the South Korean government passed its first legislation on HIV infection in 1987, only one case of HIV infection had been reported in South Korea. By

January 2014, the cumulative number of HIV-infected people in South Korea was estimated at 8,544 (Korean AIDS Information Center, 2014). However, given the fact that many people have not yet been diagnosed with HIV or do not reveal themselves as infected because of the fear of social stigma, the true number of people infected with HIV could be 5 to 10 times as many as the reported cases (Jung & Cho, 2013).

In addition, although the number of HIV-infected people is increasing, the onset of fully developed AIDS and the time to death have lengthened because of the development of more effective antiretroviral drugs and treatment. As a result, HIV infection is now considered a manageable chronic illness similar to hypertension or diabetes (Colvin, 2011). The South Korean Ministry of Health and Welfare has implemented multifaceted strategies to improve the quality of life of people living with HIV (PLWH). As part of the governmental effort, the South Korea Centers for Disease Control and Prevention has taken the initiative to promote a free peer caring service by PLWH for terminally ill HIV-infected patients since 2007 (HIV/AIDS Network Committee for Human Rights, 2002).

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In Korea, PLWH have become a serious social concern because most have been abandoned by their own families, which has caused a problem with receiving family care, and aggravated the financial burdens of medical expenses. Recipients of the peer caring service in South Korea include those who are in the terminal phases of HIV infection and experiencing symptoms such as dementia, paralysis, psychiatric disorders, and co-occurring communicable diseases.

However, PLWH who were serving as peer caregivers for terminally ill HIV-infected patients were lacking adequate knowledge about HIV as well as real-life caring experiences, which led to the development of a simulation-based training program using standardized patients (SP). When using an SP, PLWH caregiver trainees can react to the SP as a real-life patient, and acquire knowledge and skills required for caring for terminally ill patients.

Our study was conducted to develop a simulation-based PLWH peer caregiving training program, using SPs who were selected from the participants, followed by exploring the meaning of caregiving practice perceived by PLWH caregivers, using qualitative content analysis.

Methods

Participants

Participants for this study were recruited from PLWH who had registered at the South Korea Federation for HIV/AIDS through a mail process. Thirty-two PLWH volunteered to participate in the simulation-based training program.

Ethical Considerations of Subjects

Before conducting our study, approval was granted by the Institutional Review Board of the Red Cross College of Nursing. Although our study was not intended to pose any danger to participants, various efforts were carefully made to ensure the protection of the participants' human rights. Specifically, the principle of voluntary participation was employed in both simulation and survey. In addition, the participants were informed that the data collected were treated with full confidentiality, that personal information

was not disseminated or used for any purpose other than this study, and that the participants could withdraw themselves from the study at any time if they wished to do so. The Institutional Review Board confirmed that there were neither elements to this study that would deprive participants of their human rights, nor content and processes that would violate research ethics.

Simulation-based Training Program

We developed a simulation training program based on the Analysis, Design, Development, Implementation, and Evaluation (ADDIE) education framework (Morrison, 2010). The ADDIE model provided dynamic and flexible guidelines to build an effective training and instruction design.

First, in the analysis phase, along with a review of existing literature on HIV, two doctors and five nurses who were working at hospitals with terminally ill HIV-infected patients were interviewed for the purpose of identifying caring practice. In the design and development phases, scenarios for the simulation training program were created based on the results of the interviews and literature review, which included such topics as communicable disease control, HIV symptom management, personal hygiene, and daily activities and exercises. In the implementation phase, before the simulation-based training program for peer caregivers was delivered, a pretraining session was conducted with four participants who took the roles of SPs. They were asked to follow each step of the scenario in order to reveal appropriate symptoms of the terminal-stage HIV infection with a focus on emergency assessment of the patient, patient safety, personal hygiene, and mandatory notification. At the end of the simulation program, the effectiveness of the training program was measured in terms of the levels of satisfaction with the program, communications with SPs, and caregiving skills, followed by interviews for exploring the meaning of caregiving in the participants.

Data Collection and Analysis

Data were collected from October 29 to October 30, 2011. Interviews were conducted with groups of two to three participants. The interviews with each

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