

# The International Nursing Network for HIV/AIDS Research

## Background and Goals

In 1994, nurse researchers from Botswana, Swaziland and USA created the International Nursing Network for HIV/AIDS Research to respond to the devastation of HIV/AIDS around the world. Since then, The Network has provided a framework for collaborative research related to HIV/AIDS and nursing, and has linked HIV/AIDS nurse scientists who are fighting the disease in their own settings.

In many parts of the world, nurses are the primary caregivers for people living with HIV/AIDS (PLHIV). They may, however, lack information about new, evidence-based care developments, and are often left out of the research process. Therefore, The Network's goals are:

- To improve the quality of care for persons living with and affected by HIV/AIDS;
- To link nurse scientists and clinicians working in HIV/AIDS;
- To participate in developing an international agenda for HIV/AIDS nursing research;
- To generate cross-cultural and cross-national research in HIV/AIDS;
- To promote the active involvement of nurse researchers throughout the world; and
- To identify / train nurse scientists.

While The Network uses a variety of strategies to achieve these goals, it is most known for its five international collaborative research projects.



## Study I: Predictors of Adherence in HIV/AIDS

This study looked at relationships between health-related quality of life and medication adherence in 728 people living with HIV in seven cities in the USA. The study found that people with more symptoms and more severe symptoms, especially depression, adhered less to medication regimens, did not follow provider advice, and missed appointments. In addition, those who reported more positive emotions (feeling comfortable and well-cared for, having a meaningful life, taking time for important things and using their time wisely) were more adherent. Participants who reported greater engagement with their care providers were more adherent.

## Study II: Symptom Management for Persons with HIV Disease

This qualitative study investigated the strategies that 422 HIV-positive people used to manage their symptoms. Participants, recruited from 5 sites in 2 countries and via a website, were asked to think of one symptom that they were having at the time of the study, and answer questions about the symptom, strategies used to deal with it and the effectiveness of those strategies. Self-care symptom management strategies included using medications, self-comforting, complementary treatments, daily thoughts and activities, changes in diet, seeking help, spiritual care, and exercise. The percentage of participants who reported self-care techniques as effective varied by symptom, from 71% for fatigue to 78% for neuropathy to 92% for depression.

## Study III: Self-care Symptom Management in HIV/AIDS

This study used the Diefenbach & Leventhal (1996) common sense model of illness representation. The study included 1,217 adults from 12 cities in Colombia, Norway, Puerto Rico, Taiwan and the USA. Sub-analyses of the data showed that study variables explained only 22.9% of the variance in life satisfaction among ethnic minority people living with HIV/AIDS. In addition, although prayer was used by many of the participants as a complementary health strategy for HIV/AIDS, non-whites were significantly more likely to use this strategy. Younger age predicted higher sexual function and older age predicted greater provider trust. Although older HIV-positive persons reported more comorbidities, they did not report more symptoms.

## The Research Process

The development and implementation of Network research studies is a collaborative process. Ideas for new studies are developed during the biannual Network meetings. Once the group has decided on a study topic, the overall Principal Investigator (PI) takes the lead in drafting the protocol and instruments, and integrating input from Network members. Each Site PI is responsible for:

- securing a data collection site, and working with the site
- the Protection of Human Subjects
- all financial and legal liabilities for her/his particular site
- Implementing The Network's study protocol without making changes other than translation

Site PIs collect data at their sites, and submit their data to the overall Study PI, who takes the lead in further cleaning the data, scoring individual instruments, and compiling one master dataset.

At Network meetings, the group decides on topics and lead authors for manuscripts based on the combined data set. All Site PIs are offered authorship on all publications from the compiled data set, and own the data from their own sites.



## Study IV: The Efficacy of the HIV/AIDS Symptom Management Manual

This study compared the efficacy of a manual designed specifically for managing HIV/AIDS symptoms (experimental group) to a general nutrition manual (control group) for reducing HIV/AIDS symptom frequency and intensity. A 775-person, repeated measures, randomized controlled trial was conducted over three months in 12 sites from the USA, Puerto Rico, and Africa. There was a significantly greater decline in symptom frequency and intensity for those using the symptom management manual, the manual showed a significantly higher helpfulness rating, and it was used more often compared to the nutrition manual. In addition, individuals with higher generalized self-efficacy had fewer and less intense symptoms than those with lower self-efficacy. A subset of individuals who identified high levels of specific symptoms also reported significantly higher substance-use behaviors, including amphetamine and injection drug use, heavy alcohol use, cigarette smoking, and marijuana use. HIV stigma independently contributed 5.3% of the explained variance in quality of life, showing stigma's significant negative impact upon quality of life. This study further showed that HIV-positive people may experience symptoms throughout the trajectory of their disease, regardless of CD4 count or classification, and suggests that providers should discuss symptoms and symptom management with their clients at all stages of the disease.

## Study V: Exploring the Role of Self-compassion, Self-efficacy and Self-esteem for HIV-positive Individuals Managing Their HIV

Based on Social Action Theory, this study explored the association of self-care concepts (self-compassion, self-efficacy, and self-esteem) with three main aspects of HIV self-management: ARV treatment adherence, HIV transmission risk behavior and HIV symptom management. A convenience sample of 2,182 PLHIV was enrolled from HIV clinics and AIDS service organizations in Canada, China, Namibia, Puerto Rico, Thailand, and USA from February 2010 to July 2011. Total social capital reported by participants was higher than average, and moderate correlations were observed between self-reported physical and psychological condition, social support, and total social capital. Participants experienced, on average, 5.7 stressful life events in the past month, and 89% of the sample had at least one such event. The study found that the relationship between stressful life events and adherence is mediated through complex associations among cultural context and degree of self-compassion, sense of coherence, and engagement with health care provider. Of all of this study's independent variables, engagement with provider made the largest contribution to both 3- and 30-day adherence.