



University of California, San Francisco International Nursing Network for HIV/AIDS Research

W.L. Holzemer RN, PhD, FAAN

Professor, Associate Dean, and Lillian & Dudley Aldous Endowed Chair in Nursing Science, UCSF School of Nursing, Department of Community Health Systems, San Francisco, CA, USA

HOLZEMER W.L. (2007) University of California, San Francisco International Nursing Network for HIV/AIDS Research. *International Nursing Review* 54, 234–242

Aim: The University of California, San Francisco International Nursing Network for HIV/AIDS Research (the Network) is an international group of nurse scientists dedicated to research and education for the purpose of improving HIV/AIDS nursing care around the world. This article describes the evolution of the Network, as well as its structure, achievements and challenges.

Background: Although HIV/AIDS has been around for over 25 years, millions of people are still affected by the disease every year. Joint United Nations Programme on HIV/AIDS (UNAIDS) reported that in 2005, there were 38.6 million people living with HIV around the world. In many parts of the developed and developing world, nurses are the primary caregivers for people living with HIV/AIDS, and they need up-to-date information about the daily management of the disease. The Network was established to respond to the need of HIV/AIDS nurses for relevant information to inform clinical care. The Network's main activity is a series of international multi-site collaborative research studies. Past studies have addressed issues such as medication adherence, symptom management and self-care for people living with HIV/AIDS. The Network also hosts semi-annual meetings as well as a biannual international nursing science conference.

Conclusion: The Network's flexible structure has proven to be one of its greatest assets, as well as a challenge. Although the Network faces challenges, it has proven to be a useful framework for conducting international collaborative activities related to HIV/AIDS and nursing science.

Keywords: Collaborative Research, Community of Practice, HIV/AIDS, International, Network, Nursing, Research

In the mid-1980s, two nurse researchers began a collaboration that would continue for over two decades and form the foundation of the University of California, San Francisco (UCSF) International Nursing Network for HIV/AIDS Research (the Network). Since its official launch in 1995, the Network has provided a framework for collaborative research related to HIV/AIDS and nursing. Perhaps more importantly, it has served as a mecha-

nism for linking HIV/AIDS nurse scientists from around the world who are struggling to understand and fight the disease in their own settings.

Background

Joint United Nations Programme on HIV/AIDS (UNAIDS) reports that in 2005, there were 38.6 million people living with HIV around the world. During the same year, 4.1 million people were newly infected with the disease, and 2.8 million people died from AIDS (UNAIDS 2006). It has been estimated that since the beginning of the pandemic, over 25 million people around the world have died from HIV/AIDS (UNAIDS 2005). Although the

Correspondence address: William L. Holzemer, UCSF School of Nursing, Department of Community Health Systems, 2 Koret Way, Box 0608, San Francisco, CA 94143-0608, USA; Tel: 1-415-476-2763; Fax: 1-415-476-6042; E-mail: bill.holzemer@nursing.ucsf.edu.

disease has reached all parts of the world, a disproportionate number of infections and deaths have occurred in the developing world. Sixty per cent of HIV-positive people in the world live in sub-Saharan Africa. The region was home to 65% of new infections in 2005 although only 10% of the world's population lives there (UNAIDS 2005). Recent United Nations figures document that India now has as many people living with HIV as does South Africa (UNAIDS 2006). The pandemic is affecting global economies, security, development, growth and health. And while antiretroviral treatments have made it possible to manage HIV/AIDS as a chronic illness in developed countries, people living in other countries lack access to such treatments, further deepening existing disparities.

In many parts of the world, in both developed and developing countries, nurses are the primary caregivers for people living with HIV/AIDS. Though they manage much of the day-to-day care and treatment of people living with HIV/AIDS, nurses often lack information about new, evidence-based care developments. In addition, they are often left out of the research process, as investigators, subjects and experts. The Network was designed to address these issues by including nurses in carrying out research related to HIV/AIDS care, in order to improve clinical care for people living with HIV/AIDS. In addition, the Network was developed to promote international, cross-cultural perspectives on HIV/AIDS nursing and to improve the capacity of nurses to carry out their own research.

First connections

While working on a safe motherhood project in Africa in the mid-1980s, William Holzemer from UCSF met Nonhlanhla Sukati from the University of Swaziland and, even after the project ended, the two nurses' common interests helped them to maintain contact. In 1995, the University of Botswana hosted a meeting of World Health Organization (WHO) Collaborating Centers for Nursing and Midwifery in Gaborone. At that meeting, the Centers were invited to explore collaborative research opportunities, and the idea for a network focusing on HIV/AIDS nursing research was born. Shortly after this meeting, Holzemer began communicating with other colleagues interested in HIV/AIDS nursing. In 1995, he and Carmen Portillo formalized the UCSF International Nursing Network for HIV/AIDS Research.

Network goals

The overarching belief of the Network is that HIV/AIDS continues as a significant threat to public health throughout the world. The generation and sharing of nursing research has the potential to positively influence quality of care and patient outcomes across the spectrum of HIV disease. This mission is best achieved

through the ongoing collaboration of nurse scientists throughout the world. The goals of the Network, as agreed upon at the first meeting in 1996, 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 research in nursing,
- 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 and train nurse scientists.

The Network uses a variety of strategies to accomplish these goals and objectives:

- develop and implement an international HIV/AIDS nursing research programme,
- foster communication among Network participants,
- share conceptual, methodological and technical expertise,
- conduct cross-cultural, cross-national nursing research studies and disseminate the findings, and
- establish international nursing research database in HIV/AIDS.

The Network is most known for its international collaborative research projects. Since its inception, the Network has completed three such studies related to HIV/AIDS and nursing, and is currently collecting data for its fourth (see Table 1). Based on this work, participating researchers have published articles in peer review journals, and have had abstracts accepted at three International AIDS conferences.

Structure

The Network structure begins with an open membership. Anyone who is interested in HIV/AIDS nursing is welcome and is invited to join through the website (<http://www.aidsnursingucsf.org>). This includes both nurses and non-nurses, as well as students, faculty members and practising nurses.

The Network is based at UCSF's School of Nursing, within the School's Department of Community Health Systems. Holzemer and Portillo are Co-directors of the International Center for HIV/AIDS Research and Clinical Training in Nursing (International HIV Center), and the Network, directed by Holzemer, is an activity of the Center. As part of a larger Center and School, the Network has access to, if not direct funding for, staff and other resources.

Communications

Each year, the Network holds two in-person meetings. The first usually takes place in San Francisco in January or February. The second meeting location is selected based on timing and

Table 1 International collaborative Network studies**Study I: Predictors of Adherence in HIV/AIDS**

US sites: Birmingham, Alabama; Boston, Massachusetts; Highland, New York; Honolulu, Hawaii; Oakland, California; Sacramento, California; San Francisco, California; Seattle, Washington; Tampa, Florida

International sites: London, England; Oslo, Norway; Sao Paulo, Brazil

Study II: Symptom Management for Persons with HIV Disease

US sites: Boston, Massachusetts; New York, New York; Palo Alto, California; Patterson, New Jersey; San Francisco, California

International sites: Oslo, Norway

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

US sites: Boston, Massachusetts; Columbus, Ohio; Fall River, Massachusetts; Fresno, California; Harlingen, Texas; New York, New York; Patterson, New Jersey; Richmond, Virginia; San Francisco, California; San Juan, Puerto Rico; Temple, Texas; Wilmington, North Carolina

International sites: Bogota, Colombia; Oslo, Norway; Taipei, Taiwan

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

US sites: Boston, Massachusetts; Chicago, Illinois; Corpus Christi, Texas; Harlingen, Texas; Houston, Texas; Philadelphia, Pennsylvania; Salt Lake City, Utah; San Diego, California; San Francisco, California; San Juan, Puerto Rico; Vega Baja, Puerto Rico

International sites: Nairobi, Kenya; Gauteng, South Africa; Mbabane, Swaziland

convenience, and is often attached to another meeting taking place at the same time. Past meeting sites have included Bethesda, Boston, Cape Cod, Minneapolis, New Orleans, New York, Bela Bela, Chiang Mai, Gaborone, London, San Juan and Taipei.

Between meetings, almost all communications are via email and the web. In order to facilitate the growing number of members, the Network created a listserv, which now includes over 300 people. General emails are sent to the entire listserv. For specific activities, such as meeting or study participation, a general invitation is sent out on the listserv, and detailed follow-up communications are sent only to those who decide to participate. The Network also maintains a website with synchronous and asynchronous capabilities. Communal documents such as study protocols, instruments and meeting reports are posted on the website for easy access by registered members.

The Network has also begun holding a biannual nursing research conference. The conference is timed and located around the International AIDS Conferences, but is independent. The first conference took place in 2004 in Chiang Mai, Thailand, just prior to the XV International AIDS Conference in Bangkok. The second took place in Toronto, Canada, just prior to the 2006 XVI International AIDS Conference. This arrangement allows Network members to present their research at either conference, and to attend both, ultimately reducing travel expenses, and also raising the profile of nurse researchers. Approximately 100 people from 20 countries attended the first conference, and approximately 85 people from 15 countries attended the second. This international reach is one of the main reasons that people join the Network, as it allows them to meet and establish relationships with people from around the world. The Office of AIDS Research at the National

Institutes of Health (NIH) has generously funded scholarships for both conferences.

Management of collaborative research

As participation in the Network's collaborative studies has grown, guidelines and processes have been developed to clarify issues such as authorship, ownership of data and protocol development. Ideas for studies are developed during Network meetings, usually over the course of approximately 1 year. Once the group has decided on a study topic, UCSF takes the lead in drafting the protocol and instruments, and integrating input from all Network members. During this process, Network members also begin their individual processes of deciding whether to participate as a Site Director and gathering resources.

Any Network member who has the expertise to fulfill Principal Investigator responsibilities may serve as a Site Director. Students are not allowed to be Site Directors, but are encouraged to find other ways to participate such as assisting a Site Director, providing input in the development of protocols and instruments, or authoring articles and abstracts based on the data and their own analyses. Guidelines for Site Director roles and responsibilities are as follows:

- The Site Director serves as the Principal Investigator, as defined by the National Institutes of Health, for her or his particular site;
- The Site Director is responsible for securing a data collection site, and for working with that site. Sites should not be confused with academic institutional affiliation, as it is possible that several sites may be affiliated with a single university;
- The Site Director is responsible for the Protection of Human Subjects, including seeking, securing and updating Human

Subjects Research Certification; securing Institutional Review Board/Ethical Committee approval for her or his particular site; and maintaining the confidentiality of participant's records; and

- The Site Director incurs all financial and legal liabilities for her or his particular site.

Each Site Director agrees to implement the Network's protocol without making changes other than adding questions to the instrument or translating the instruments into the local language. If a particular site conducts the study in a language other than English, the Site Director agrees to provide electronic files of all translated study documents to UCSF.

Site Directors then collect data at their sites, and submit their data to UCSF for compilation with other sites' data. Data can be submitted in one of two ways. UCSF provides all Site Directors with an SPSS template that can be used for data entry and then submitted to UCSF via email. If Site Directors choose to use this method, they are responsible for cleaning the raw data before submitting it. For Study IV, Site Directors have also been given the option of entering the data through a website which was designed and is maintained by UCSF. The website validates much of the data as it is entered, resulting in cleaner raw data sets. Once a Site Director has completed data entry through the website, UCSF sends her or him an SPSS file of the site's data in return.

Once the data from all sites have been submitted, UCSF takes the lead in further cleaning the data and compiling one master raw data file. Individual instruments are then scored, and a second master file is created. All Site Directors receive a copy of the compiled data files. A study's data set is considered open for analysis until a majority of Site Directors from the study vote to close it.

All Site Directors are offered authorship on all publications and presentations from a compiled open data set, and may choose to participate at their discretion. Because first or second authorship is the primary mechanism for determining credit for scientific advances and thus the primary basis for assessing a scientist's contributions to developing new knowledge, authorship of any article based on Network data is considered a benefit and a responsibility. For each individual, the privilege of authorship is based on a significant contribution to the conceptualization, design, execution and/or interpretation of the research study, as well as a willingness to assume responsibility for the study.

The first author is the person who proposes the study question for the article and takes on the responsibility to produce the article. In most cases, two or three other people will be closely involved in the analysis and writing of the article. The order of their names is based on their contribution to the article, and discussion among themselves. All other Site Directors are listed after this initial team, and names are rotated for all articles, so that no name always appears first or last.

Data sets are labelled as 'open' while the team is continuing to analyse and publish from the data set. When the primary manuscripts are completed, a data set is 'closed'. A Site Director who is interested in conducting analysis on a closed data set must request permission from the Network, mainly in order to foster communication among all parties. Access to closed data sets by those who were not Site Directors for that study may be granted upon receipt of a request that includes the intended purpose of use, agreement to acknowledge the source of the data set in all presentations and publications, and agreement to submit a copy of the publication to the Network for recordkeeping purposes. Authorship of these articles and presentations is at the discretion of the first author, and does not need to include all of the Site Directors because the analysis constitutes a secondary analysis.

All Site Directors own the data from their own sites. Therefore, a Site Director may do posters, presentations or articles about their own site data without the permission of the Network, as long as the Network is acknowledged as a collaborator.

Resources

The Network operates based on existing sources of funding at UCSF, which are channelled through the International HIV Center. These funds support:

- the annual meeting in San Francisco,
- coordination of the overall collaborative research studies (logistics, communications and data management),
- data collection for UCSF's participation in the collaborative research studies,
- the international conferences,
- maintenance of the Network's website and listserv,
- maintenance of Network records,
- office space, and
- staff support.

When meetings take place at locations other than UCSF, one or more Network members volunteer to organize the meeting and take on some of that financial responsibility.

For the collaborative studies, each Site Director is responsible for identifying resources to conduct the study at her or his site, and this often comes as small grants from their universities, or other small sources of funds. UCSF provides overall coordination and data management for these studies. Because the Network is based in a university setting, students have participated in the collaborative studies as part of their research residencies, and thus provided a great deal of additional staff time for data management of the studies. This is an opportunity for them to acquire research skills and to meet other nurse scientists in their field. Several of the people who have participated in studies as graduate students have become active members of the Network and served as Site Directors later in their careers.

The Network's activities ultimately enhance much of the other HIV/AIDS nursing training and research taking place at the UCSF School of Nursing. For this reason, the staff members who support the Network (particularly the annual meetings and the collaborative studies) are paid by UCSF funds. The Department of Community Health Systems provides office space for the Network.

Challenges

The main challenge for the Network has been the ongoing difficulty of securing resources to support the work. Although the Network made the decision that each Site Director must secure funds for her or his own site, there are additional sites (particularly international sites) that would join the work if modest funds were available. UCSF has been able to sustain the Network with School of Nursing support for the International HIV/AIDS Center, although these funds have now been discontinued. The Network has also made several applications to foundations for support for its activities, but was only successful once several years ago. The NIH grant application model is very challenging for this type of collaborative research given the challenge of developing protocols across sites (nationally and internationally) and then building a budget that allows direct costs and indirect recovery rates at the site level and overall level. Despite this, the Network continues to explore opportunities to support its work financially.

Another challenge for the Network has been its very structure. Although the Network is based at UCSF, in reality it is a loosely knit group of people who share common interests, sometimes called a community of practice (Compernelle & Bailey 2005). This is useful in that it allows for a great deal of flexibility. Members are invited but not obligated to attend meetings. They can decide not to participate in one study, but then to return for another. And they are free to collaborate with each other outside the Network. At the same time, however, the structure results in certain challenges. One of the main challenges has been leadership. Currently, the Network is operated out of UCSF, mainly because it was established by two UCSF faculty members, and because of their continued commitment to the work. The Network has at various times discussed whether to transition leadership, but no other person or institution has volunteered, and no decision has ever been reached about how or when to effect such a transition.

Contributions

Although the Network has always faced a variety of challenges, the commitment of its members has resulted in substantial contributions to the area of HIV/AIDS in general, and HIV/AIDS nursing in particular. The three completed multi-site studies have added to the knowledge base about HIV/AIDS symptoms,

adherence and self-care, and the results have been disseminated in a variety of multi-authored peer review publications, presentations and posters (Table 2). The Network is also registered with the National Institutes of Health Roadmap initiative's Inventory and Evaluation of Clinical Research Networks (<http://www.clinicalresearchnetworks.org>).

The first study, 'Predictors of Adherence in HIV/AIDS', looked at relationships between health-related quality of life and medication adherence in 728 people living with HIV in seven cities in the USA (Bakken et al. 2000; Corless et al. 2000; Holzemer et al. 1999a,b; Nokes & Bakken 2002; Nokes et al. 2000). 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 (Holzemer et al. 1999a). Participants who reported greater engagement with their care providers were more adherent (Bakken et al. 2000). Symptom status also contributed to cognitive functioning.

The second study, 'Symptom Management for Persons with HIV Disease', investigated the strategies that 422 HIV-positive people used to manage their symptoms (Bunch 2004; Corless et al. 2002; Eller et al. 2005; Kempainen et al. 2003; Kirksey et al. 2002; Nicholas et al. 2002). Participants were recruited from five sites in two countries, and via a website. Participants 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 the symptom and the effectiveness of those strategies. Using qualitative data analysis techniques, the investigators found that the 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 (Chou et al. 2004). The percentage of participants who reported self-care techniques as effective varied by symptom, from 71% for fatigue (Corless et al. 2002) to 78% for neuropathy (Nicholas et al. 2002) to 92% for depression (Eller et al. 2005).

The third study, 'Self-care Symptom Management in HIV/AIDS', used the Diefenbach & Leventhal (1996) common sense model of illness representation to explore relationships among the six constructs of the theory: person, illness representation, symptom self-care, perceived effectiveness of self-care activities, adherence and outcomes appraisal. The study included 1217 adults from 12 cities in the USA, as well as Puerto Rico, Taiwan, Norway and Colombia (Coleman et al. 2006; Portillo et al. 2005). Sub-analyses of the data showed that variables included in the study explained only 22.9% of the variance in life satisfaction

Table 2 Network publications, posters and abstracts

Study I: Predictors of Adherence in HIV/AIDS

Publications

- 1999 Holzemer, W.L. et al. Predictors of self-reported adherence in persons living with HIV disease. *AIDS Patient Care and STDs*, 13 (3): 185–197.
- 1999 Holzemer, W.L. et al. Validation of the Sign and Symptom Check-list for persons living with HIV disease (SSC-HIV). *Journal of Advanced Nursing*, 30 (5): 1041–1049.
- 2000 Bakken, S. et al. Relationships between perception of engagement with healthcare provider and demographic characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care and STDs*, 14 (4): 189–197.
- 2000 Corless, I.B. et al. Predictors of perception of cognitive functioning in HIV/AIDS. *Journal of Association of Nurses in AIDS Care*, 11 (3): 19–26.
- 2000 Nokes, K.M. et al. Health-related quality of life in persons younger and older than 50 who are living with HIV/AIDS. *Research on Ageing*, 22 (3): 290–310.
- 2002 Nokes, K.M. & Bakken, S. Issues associated with measuring symptom status: HIV/AIDS case illustration. *Journal of the New York State Nurses Association*, 33 (2): 17–21.

Abstracts from the 12th International AIDS Conference, Geneva, 28 June–3 July 1998

- 1998 Gir, E., Pratt, R., Bunch, E. & Holzemer, W.L. Adherence to antiretroviral therapy: A four-country comparison.
- 1998 Nokes, K.M. et al. Are there gender difference in HIV adherence?
- 1998 Brown, M.A. et al. Social support and adherence in HIV+ persons.
- 1998 Powell-Cope, G.M. et al. Perceived healthcare providers support and HIV adherence.
- 1998 Turner, J.B. et al. History of drug use and adherence in HIV+ persons. Oral Presentation 391.
- 1998 Holzemer, W.L. et al. Psychological well-being and HIV adherence.
- 1998 Corless, I.B. et al. Cognition and HIV adherence.

Study II: Symptom Management for Persons with HIV Disease

Publications

- 2002 Corless, I.B. et al. Self-care for fatigue in HIV disease. *Oncology Nursing Forum*, 29 (5): E60–E69.
- 2002 Kirksey, K. et al. Complementary therapy use in Persons with HIV/AIDS. *Journal of Holistic Nursing*, 20 (3): 264–78.
- 2002 Nicholas, P.K. et al. Self-care management for neuropathy in HIV disease. *AIDS Care*, 14 (6): 763–71.
- 2003 Kemppainen, J.K. et al. Self-care management of anxiety and fear in HIV disease. *Journal of the Association of Nurses in AIDS Care*, 14 (2): 21–29.
- 2004 Bunch, E.H. Symptom management for HIV-positive persons in Norway. *International Nursing Review*, 51: 167–175.
- 2004 Chou, F.Y., Holzemer, W.L., Portillo, C.J. & Slaughter, R. Self-care strategies and sources of information for HIV/AIDS symptom management. *Nursing Research*, 53 (5): 332–9.
- 2005 Eller, L.S. et al. Self-care strategies for depressive symptoms in people with HIV disease. *Journal of Advanced Nursing*, 51 (2): 119–130.

Abstracts from the 13th International AIDS Conference, Durban, South Africa, 10–14 July 2000, Reprinted in Journal of the Association of Nurses in AIDS Care

- 2000 Holzemer, W. et al. Self-care for diarrhea in HIV disease.
- 2000 Kemppainen, J. et al. Anxiety and fear in HIV disease.
- 2000 Eller, L. et al. Self-care for depression in HIV disease.
- 2000 Corless, I. et al. 'Fatigue Big Time': fatigue and weakness in HIV disease.
- 2000 Nicholas, P. et al. Self-care for peripheral neuropathy in HIV disease.

Other Abstracts

- 2001 Kirksey, K. et al. HIV symposium, adherence, and quality of life for people living with HIV/AIDS. *Communicating Nursing Research Conference Proceedings*, Volume 34, Western Institute of Nursing, pp. 129–134.
- 2001 Chou, F.Y. & Holzemer, W.L. HIV symptom management strategies: A web-based study. *22nd International of Nurses Quadrennial Congress*, Copenhagen, p. 34.
- 2001 Holzemer, W.L. International HIV/AIDS Nursing Research Network. Abstracts for concurrent sessions. *International Council of Nursing*, Copenhagen, June 10–15, 2001, p. 85.

Table 2 Continued

- 2001 Nokes, K. et al. Self-care strategies for nausea/vomiting by persons with HIV disease. *Association of Nurses in AIDS Care Symptom Preconference*, Puerto Rico. Reprinted: *Journal of the Association of Nurses in AIDS Care*, 12, Supplement, p. 101.
- Study III: Self-care Symptom Management in HIV/AIDS
- Publications
- 2005 Portillo, C.J. et al. Quality of life of ethnic minority persons living with HIV/AIDS. *Journal of Multicultural Nursing & Health*, 11 (1): 31–37.
- 2006 Coleman, C.L. et al. Prayer as a complementary health strategy for managing HIV-related symptoms among ethnically diverse patients. *Holistic Nursing Practice*, 20 (2): 65–72.
- Abstracts from the 15th International AIDS Conference, Bangkok, Thailand, 11–16 July 2004
- 2004 Cashen, M.S. et al. Impact of literacy skills in individuals with HIV.
- 2004 Corless, I.B. et al. Symptom management in HIV/AIDS: fatigue.
- 2004 Corless, I.B. et al. Fatigue related to HIV/AIDS and comorbidities.
- 2004 Dole, P.J. et al. Affect of alcohol on HIV+ individuals' well-being and adherence.
- 2004 Kempainen, J.K. et al. Anxiety self-care symptom management.
- 2004 Kirksey, K.M. et al. Predictors of body changes in persons with HIV/AIDS.
- 2004 Nicholas, P.K. et al. Self-care symptom management for peripheral neuropathy in HIV disease.
- 2004 Portillo, C.J. et al. Three public health epidemics impacting the health of women.
- 2004 Reynolds, N.R. et al. Illness representations of HIV and their relation to health outcomes.
- 2004 Reynolds, N.R. et al. Type, frequency, and effectiveness of nausea self-care management strategies: An international, multi-site study.
- 2004 Sanzero Eller, L. et al. Predictors of four dimensions of depressive symptoms in people living with HIV.
- 2004 Sanzero Eller, L. et al. Self-care strategies for depression in people living with HIV.
- 2004 Sefcik, E.F. et al. Demographic differences in HIV/AIDS illness representation.
- 2004 Voss, J. et al. Impact of fatigue on daily activities and adherence to ARV medications.
- 2004 Wantland, D.J. et al. Self-reported symptoms in HIV+ persons receiving and not receiving ARVs.
- Abstracts from the 16th International AIDS Conference, Toronto, Canada, 13–18 August 2006
- 2006 Eller, L.S. et al. Cultural Differences in Predictors of Depression.
- 2006 Holzemer, W.L. et al. Does asymptomatic mean without symptoms?
- 2006 Lindgren, T. et al. Using Cluster Analysis To Describe People Living With HIV'S Symptom Experience.
- 2006 Nokes, K.M. et al. Health literacy, health outcomes, and healthcare service use in HIV + persons in the USA.
- 2006 Corless, I.B. et al. Use and Perceived Effectiveness Of Marijuana As a Self-care Strategy For Six Symptoms.
- Study IV: The Efficacy of the HIV/AIDS Symptom Management Manual
- Abstracts from the 16th International AIDS Conference, Toronto, Canada, 13–18 August 2006
- 2006 Rosa, M. et al. Meeting the Requirements of Committees for the Protection of Human Subjects.
- 2006 Moezzi, S. et al. Testing the Efficacy of the UCSF HIV/AIDS Self-Care Symptom Management Manual.
- 2006 Holzemer, W.L. et al. Development of the UCSF HIV/AIDS Self-Care Symptom Management Manual.

among ethnic minority people living with HIV/AIDS (Portillo et al. 2005). 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 (Coleman et al. 2006).

The fourth study, 'The Efficacy of the HIV/AIDS Symptom Management Manual', is a randomized controlled trial comparing the efficacy of a manual designed specifically for managing HIV/AIDS symptoms (experimental group) to a general nutrition manual (control group) at three points in time. The study is being conducted in nine cities in the USA, and in Kenya, Puerto

Rico, South Africa and Swaziland, and almost 800 people have been recruited to date.

The Network strives not only to conduct research and disseminate results, but also to translate this work into practice. Based largely on the results of the second collaborative study, a group of UCSF pre-doctoral and postdoctoral students participating in an advanced HIV seminar worked with faculty to draft the first version of *Symptom Management Strategies: A Manual for People Living with HIV/AIDS* (San Francisco Regents 2004). In subsequent years, the manual was developed further based on additional research carried out in Botswana, Lesotho, South Africa and

Swaziland ('Self and Family Care Symptom Management for Persons Living with HIV Disease', Bristol-Myers Squibb Company's *Secure the Future Foundation*, RES009, Holzemer). The self-care symptom management strategies have also been the basis for an interactive HIV self-care website (<http://www.hivnurse.us/ssc/sscwelcome.htm>). Though a great deal of anecdotal evidence supports the efficacy of the manual, the Network decided to build upon this and conduct the randomized controlled trial (the fourth collaborative study) to produce quantifiable information regarding efficacy. As a result of these combined efforts, the manual has been translated into at least five languages and thousands of copies have been distributed in southern Africa. In addition, all versions of the manual are available for free download on the Network's own website.

Another important contribution has been the Network's focus on building capacity. As mentioned previously, several doctoral and postdoctoral students have worked on Network studies, and gone on to become faculty members and Site Directors later in their careers. Secondary analysis of Network data has been the basis of more than one doctoral dissertation. In this respect, the Network provides an important mentoring service. Participation in the Network also serves to build the capacity of seasoned faculty by honing research skills, and exposing faculty to topic areas, which they may not previously have considered. It also helps raise awareness of opportunities for enrichment. For example, a faculty member from an East Coast university learned about a postdoctoral training programme (National Institutes of Health T32 NR07081, Holzemer) at UCSF through her participation in the Network, and in 2003–2004 participated in the programme. Publication and presentation of research results from Network studies also adds to faculty members' curricula vitae, providing added support for promotions.

The Network is now working closely with the WHO Office of Nursing and Midwifery to lead its Community of Practice on HIV/AIDS. This will include building on the existing functionality of the Network's website, as well as finding new ways to engage nurse researchers and bedside nurses in discussions of best practices in HIV/AIDS research and care.

Conclusion

As HIV/AIDS continues to spread to all countries and communities around the world, it is important to identify new ways to collaborate at an international level to improve care for those people affected by the disease. The Network is an innovative system, through which nurse scientists participate in and influence research that can ultimately be translated into improved care for HIV-positive people. Because all Network members participate in developing the research, it is truly cross-cultural and thus relevant at an international level. In addition, the Network provides a

means for disseminating the research, as well as opportunities for both junior and senior investigators to strengthen their research skills. The Network's work on adherence, symptom management, quality of life and living well with HIV/AIDS contributes to our understanding that living with HIV/AIDS, though challenging, can be supported by nurses and other healthcare providers while most people live most of their lives independently outside the healthcare system.

Acknowledgements

The Network would like to acknowledge the ongoing support of the UCSF School of Nursing, particularly the Dean's Office and the Department of Community Health Systems.

References

- Bakken, S. et al. (2000) Relationships between perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care and STDs*, **14** (4), 189–197.
- Bunch, E.H. (2004) Symptom management for HIV-positive persons in Norway. *International Nursing Review*, **51** (3), 167–175.
- Chou, F.Y., Holzemer, W.L., Portillo, C.J. & Slaughter, R. (2004) Self-care strategies and sources of information for HIV/AIDS symptom management. *Nursing Research*, **53** (5), 332–339.
- Coleman, C.L. et al. (2006) Prayer as a complementary health strategy for managing HIV-related symptoms among ethnically diverse patients. *Holistic Nursing Practice*, **20** (2), 65–72.
- Compernelle, L. & Bailey, C. (2005) *Communities of Practice: A Review of Existing Literature (Draft)*. World Health Organization, Geneva.
- Corless, I.B. et al. (2000) Predictors of perception of cognitive functioning in HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, **11** (3), 19–26.
- Corless, I.B. et al. (2002) Self-care for fatigue in patients With HIV. *Oncology Nursing Forum*, **29** (5), E60–E69.
- Diefenbach, M.A. & Leventhal, H. (1996) The common sense model of illness representation: theoretical and practical considerations. *Journal of Social Distress and the Homeless*, **5**, 11–38.
- Eller, L.S. et al. (2005) Self-care strategies for depressive symptoms in people with HIV disease. *Journal of Advanced Nursing*, **51** (2), 119–130.
- Holzemer, W.L. et al. (1999a) Predictors of self-reported adherence in persons living with HIV disease. *AIDS Patient Care and STDs*, **13** (3), 185–197.
- Holzemer, W.L. et al. (1999b) Validation of the sign and symptom check-list for persons with HIV disease (SSC-HIV). *Journal of Advanced Nursing*, **30** (5), 1041–1049.
- Kempainen, J.K. et al. (2003) Self-care management of anxiety and fear in HIV disease. *Journal of the Association of Nurses in AIDS Care*, **14** (2), 21–29.
- Kirksey, K.M. et al. (2002) Complementary therapy use in persons with HIV/AIDS. *Journal of Holistic Nursing*, **20** (3), 264–278.

- Nicholas, P.K. et al. (2002) Self-care management for neuropathy in HIV disease. *AIDS Care*, **14** (6), 763–771.
- Nokes, K.M. & Bakken, S. (2002) Issues associated with measuring symptom status: HIV/AIDS case illustration. *Journal of the New York State Nurses Association*, **33** (2), 17–21.
- Nokes, K.M. et al. (2000) Health-related quality of life in persons younger and older than 50 who are living with HIV/AIDS. *Research on Aging*, **22**, 290–310.
- Portillo, C. et al. (2005) Quality of Life of Ethnic Minority Persons Living with HIV/AIDS. *Journal of Multicultural Nursing and Health*, **11** (1), 31–37.
- San Francisco Regents. (2004) *Symptom Management Strategies: A Manual for People Living with HIV/AIDS*. University of California, San Francisco Regents, School of Nursing, San Francisco, CA.
- UNAIDS (2005) *AIDS Epidemic Update*. UNAIDS, Geneva.
- UNAIDS (2006) *2006 Report on the Global AIDS Epidemic*. UNAIDS, Geneva.