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President's Message—The International Nursing Network for HIV Research

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1 **President’s Message**

2 **The International Nursing Network for HIV Research**

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4 It is hard to believe that with this issue of *JANAC* we approach the 40<sup>th</sup> year of the HIV  
5 epidemic. From the beginning, ANAC and its members have always been part of the response,  
6 from being a place for nurses to find support and connection, to serving as a clearinghouse for  
7 state-of-the-science information on clinical care and HIV treatments, to leading policy change to  
8 respond to disparities in care, to engaging in research to advance knowledge about HIV. And,  
9 ANAC members continue to meet the challenges of the epidemic every day.

10 As part of this *JANAC* special issue on the State of Nursing Science throughout the  
11 Epidemic, we are proud to highlight the work of the International Nursing Network for HIV  
12 Research, *aka* “The Network” – an affiliate of ANAC since 2014. As one of ANAC’s strategic  
13 objectives, facilitating research to advance nursing science in HIV is essential to our mission,  
14 and working through The Network allows us to build on the expertise of leading international  
15 nurse scientists, while providing a structural home for The Network. This win-win affiliation has  
16 strengthened ANAC’s capacity and reputation as a national leader in HIV research and  
17 prevention, care, and treatment, and created a stronger affiliation for the many people who are  
18 active members of both ANAC and The Network.

19 **Some History**

20 In 1995, Drs. William Holzemer and Carmen Portillo established the International  
21 Nursing Network for HIV/AIDS Research at the University of California, San Francisco (UCSF)  
22 School of Nursing (USA), as a collaborative endeavor of nurse scientists committed to  
23 improving the quality of HIV care through research (Holzemer, 2007). Over the years,

24 membership in The Network has grown to more than 300 individuals, representing nursing as  
25 well as disciplines such as sociology, education, public health, and psychology. As The Network  
26 became affiliated with ANAC, Dr. Allison Webel and Dr. Craig Phillips, both members of  
27 ANAC, became Co-Directors of The Network, solidifying the collaboration.

## 28 **How The Network Works**

29         The Network is founded on the belief that the “generation and sharing of nursing research  
30 has the potential to positively influence quality of care and patient outcomes across the spectrum  
31 of HIV disease” (Holzemer, 2007, p. 235). Almost 25 years later, the continued relevance of this  
32 mission cannot be denied. To achieve the mission, The Network links nurse scientists and HIV  
33 clinicians to generate cross-cultural and global research (ANAC, 2021).

34         Although there is no formal organization to The Network, members have established  
35 guidelines to organize their research (Holzemer, 2007). The Network meets in-person twice a  
36 year; one meeting coincides with the ANAC annual conference, and the other is hosted by a  
37 Network member at their college or university. Members may submit research proposals or ideas  
38 before or at meetings and, based on discussion and interest, one idea is selected for further  
39 development and implementation. Once a research protocol is finalized, any member who meets  
40 generally recognized Principal Investigator (PI) qualifications may choose to establish a data  
41 collection site. At the completion of data collection, all data are compiled into a shared dataset by  
42 the lead site, and PIs decide on analyses, manuscripts, and authorship.

43         The Network encourages and facilitates the mentorship of novice researchers, including  
44 both students and junior faculty. Participation in The Network research studies provides doctoral  
45 students an opportunity to acquire research skills by functioning as research assistants. Once The  
46 Network completes a study, doctoral students may conduct secondary analyses on the data with

47 permission from The Network and may use these for dissertations. Several former doctoral  
48 students are now active Network members and have served as site PIs in subsequent studies.

#### 49 **The Network Studies**

50 Since its inception, The Network has made substantial contributions to HIV research,  
51 completing seven international multisite research studies, and disseminating results through  
52 many national and international conference presentations and posters. Network studies have  
53 generated more than 60 peer-reviewed publications and more than 2,000 citations in scientific  
54 journals (Perazzo et al., 2018), and have included multiple sites in cities across the United States  
55 and Puerto Rico, as well as in Botswana, Canada, China, Colombia, Kenya, Namibia, Norway,  
56 South Africa, Taiwan, and Thailand. The following is a summary of Network studies:

#### 57 **Study I: Predictors of Adherence in HIV/AIDS (1998-2002; Holzemer et al., 1999)**

58 This study showed that people who reported more HIV and AIDS symptoms and reported  
59 symptoms that were more intense – especially depression – were less adherent to their HIV  
60 medication regimens. In addition, they were less likely to follow advice from their providers and  
61 missed a greater number of medical appointments. In contrast, individuals who reported greater  
62 positive feelings and more engagement with their HIV health care providers reported greater  
63 adherence to their HIV medication regimens.

#### 64 **Study II: Symptom Management for Persons with HIV Disease (2001-2005; Chou et al., 65 2004; Corless et al., 2002; Kirksey et al., 2002; Nicholas et al., 2002)**

66 This qualitative study investigated self-care strategies that individuals use to manage their  
67 HIV symptoms, including using various medications, comforting themselves, using  
68 complementary therapies, engaging in diverse daily activities and thoughts, changing their diet,  
69 seeking help from others, turning to spirituality, and increasing exercise. Study participants rated

70 each self-care strategy, and results showed that effectiveness varied by symptom: 71% for  
71 symptoms of fatigue, 78% for symptoms of neuropathy, and 92% for symptoms of depression.

72 **Study III: Self-care Symptom Management in HIV/AIDS (2004-2008; Portillo et al., 2005;**  
73 **Reynolds et al., 2009)**

74 This study showed that, among racial and ethnic minority individuals living with HIV,  
75 constructs of illness representation (illness representation, the person, self-care of symptoms,  
76 effectiveness of self-care strategies, medication adherence, and appraisal of outcomes) only  
77 explained 23% of variance in life satisfaction. Racial and ethnic minorities were also  
78 significantly more likely to use prayer as a complementary health strategy for HIV/AIDS.

79 **Study IV: The Efficacy of the HIV/AIDS Symptom Management Manual (2007-2014;**  
80 **Wantland et al., 2008)**

81 The results of this study showed that people using a self-care symptom management  
82 manual for HIV and AIDS experienced a larger decrease in the frequency and intensity of  
83 symptoms compared to those using a nutrition manual. In addition, participants rated the  
84 symptom manual as more useful than the nutrition manual and used it more often.

85 **Study V: Exploring the Role of Self-Compassion, Self-Efficacy, and Self-Esteem for HIV-**  
86 **Positive Individuals Managing Their HIV (2011-2017; Dawson-Rose et al., 2015)**

87 This study found that PLWH with more self-compassion reported less risky sexual  
88 behavior, even when using illicit drugs. In addition, self-compassion among PLWH was related  
89 to HIV self-management, and there was a moderate relationship between social capital and self-  
90 reported psychological and physical health.

91 **Study VI: Health Literacy: People Living with HIV, Health Care Providers, and**  
92 **Professional Care Team Members (2014-2017; Dawson-Rose et al., 2016; Lindgren et al.,**  
93 **2018)**

94 Both PLWH and clinical providers participated in this focus group study to develop a  
95 more nuanced understanding of health literacy. Understanding HIV and the complex treatment  
96 needed to manage HIV was learned over time and promoted through trust between PLWH and  
97 their clinicians. The study found that understanding and trust was an iterative process that  
98 developed over time. In addition, the study found that people with HIV learned about the disease  
99 in a variety of locations, including both clinical and non-clinical locations, as well as virtual  
100 locations online.

101 **Study VII: An Ecological Understanding of Physical Activity Patterns of Adults Living**  
102 **with HIV Throughout the Lifespan (2017-2020; Webel et al., 2019)**

103 This study sought to understand how exercise and physical activity, and interpersonal and  
104 structural environmental characteristics influence chronic comorbidities using an ecological  
105 perspective. The study results describe participants as primarily engaging in light activity, which  
106 is below recommended activity levels, and that vigorous activity among women was associated  
107 with increased cardiovascular fitness. Further, the study found that use of social media was  
108 associated with higher body mass index.

109 **Study VIII: The Impact of the SARS-CoV-2 Pandemic and Shelter-in-Place / Lock-Down**  
110 **Policies on People with HIV (2021- )**

111 The Network is currently developing a protocol to explore the effect of the COVID-19  
112 pandemic on PLWH. Data will be collected from participants both online and in person.  
113 Recruitment is planned to begin in the summer of 2021.

114 **The Network Operations**

115           The Network functions on principles of inclusivity, mentorship, and collaboration. New  
116 members are welcomed to meetings and invited to participate in studies in whatever way they  
117 can. Students and junior researchers may collaborate with more senior mentors. Manuscripts  
118 include extensive author lists to acknowledge everyone’s contributions and to help junior  
119 researchers achieve publications. Study ideas are developed collaboratively, and all members can  
120 participate in decision-making. The Network’s global and interprofessional scope ensure  
121 diversity and inclusion, and its collaborative model is an exemplar for the production and  
122 dissemination of nursing research.

123           The Network invites ANAC members interested in HIV research or HIV clinical care to  
124 join. If you are interested in learning more about The Network or becoming involved in our next  
125 study, we encourage you to reach out to Carol Dawson-Rose ([carol.dawson-rose@ucsf.edu](mailto:carol.dawson-rose@ucsf.edu)) or  
126 attend our meeting at the next ANAC conference. To join our listserv, please contact Allison  
127 Webel ([awebel@uw.edu](mailto:awebel@uw.edu)). Please visit our website at:

128 <https://www.nursesinaidscare.org/i4a/pages/index.cfm?pageid=4551>

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