Advancing HIV Nursing Practice



Message from the Dean

Many people with HIV are not only living longer—they're also living well, thanks to improved treatments. About half of all Americans with HIV are 50 years of age or older. They're facing illnesses they never thought they'd live long enough to experience, from diabetes and hypertension to cardiac disease.

To address the growing need for both primary and specialty services in the HIV community, Rutgers School of Nursing launched an Advanced Practice HIV Care Specialization program five years ago, supported by a grant from the Health Resources and Services Administration (HRSA).

This publication documents how the school developed an innovative academic model combining HIV course work with intensive clinical training. Our talented faculty has risen to the challenge of integrating HIV care into the context of primary care. The goal of our program is to ensure that future generations of nurse practitioners are prepared to meet the needs of HIV patients.

We have a long history of serving the HIV community through prevention, care, treatment, and education. The strength of our commitment is reflected not only in education and service to the community, but also in our research. Faculty members in Rutgers School of Nursing's François-Xavier Bagnoud (FXB) Center, a partner in obtaining this grant, conduct important funded studies on a variety of HIV-related topics, including the impact of stigma on care. Other research and service projects are ongoing. It's all part of our mission to improve care for those living with HIV.

Sincerely, William L. Holzemer, PhD, RN, FAAN Dean and Distinguished Professor



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Training the Next Generation of HIV Nurses

Nurses have been on the front lines of HIV care since the epidemic's beginning. With improved diagnosis, treatment, and care, the number of people living with HIV continues to rise — but there aren't enough health professionals prepared to care for them.

Addressing this need, Rutgers School of Nursing developed an Advanced Practice HIV Care Specialization program to train the next generation of care providers. Supported by a five-year grant from the Health Resources and Services Administration (HRSA), the program is offered as a specialty within the school's Doctor of Nursing Practice (DNP) program.

This overview of the HIV Care Specialization program traces its beginnings and shows how it prepares nurse practitioners to assume leadership roles in providing this care. Among its achievements, the school has:

- Developed an interprofessional academic model for HIV education focused on providing quality care for individuals living with HIV/AIDS
- **Established** an innovative HIV nursing curriculum and incorporated it within the school's Doctor of Nursing Practice program
- Recruited outstanding faculty with expertise in HIV clinical care
- Identified HIV treatment sites where students train with preceptors to gain clinical experiences in underserved communities
- **Built** a program that is strong and sustainable, ensuring that future generations of nurse practitioners are prepared to meet the needs of those living with HIV

Answering a Need for Care

hen Suzanne Willard received her first nursing degree in 1984, a faculty member told the new graduates, "We're seeing a new disease and it's pretty serious. We don't know much about it, but it's probably going to affect you."

This disease is now known as AIDS. Back then, little was known about it. Science moved forward, and researchers, government and human services agencies, health professionals, and activists joined forces to develop improved



Suzanne Willard, clinical professor and director of the HIV care program

"HIV care is not just about medicine; it's about keeping people in care, helping them deal with this stigmatizing disease. Getting a diagnosis of HIV is a traumatic event." | SUZANNE WILLARD

treatments and preventions. So successful were these efforts that AIDS is now treatable as a chronic disease.

Those living longer with HIV are more likely to be affected by the chronic diseases of aging, such as diabetes and hypertension. So clinicians treating them must be well-versed in both HIV and primary care. While the HIV knowledge base has evolved, educating health providers has not kept pace. More than half of U.S. primary care physicians do not offer HIV care because they don't feel they have the appropriate skills. Additionally, the first generation of HIV providers are "graying" and approaching the end of their careers. This vacuum of care opens the door for nursing professionals to fill the gap.

HIV Collaborative for Care

Willard has been a leader in HIV prevention, care, treatment, and education initiatives for more than three decades. She was the first nurse elected to the Department of Health and Human Services Panel on Clinical Practices for Treatment of HIV Infection. She is also past president of the Association of Nurses in AIDS Care (ANAC) and received ANAC's Lifetime Achievement award in 2017.

She joined the Rutgers faculty in 2010 as an associate dean in the School of Nursing, where she was tasked with strengthening academic programs and building the school's new Doctor of Nursing Practice (DNP) program.

With a keen interest in developing a graduate-level HIV specialty care program, Willard sought funding to make this dream a reality. In the early days of the epidemic, HRSA supported training programs for health professionals through its AIDS Education and Training Centers (AETC) program. In 2013 HRSA expanded this support to nurse practitioner programs.

"We wanted to strengthen HIV content in our program to give

Keeping Care at its Core

François-Xavier Bagnoud (FXB) Center, part of the School of Nursing, began providing care in 1987 for HIV, infectious diseases, and immunologic disorders, with a focus on pediatric HIV. Its location in Newark, NJ, a city hard hit by pediatric HIV, gave it great visibility. Today the FXB Center is a leader in HIV research and care, provided at its FXB clinic. Education is a cornerstone of its mission, and FXB Center members support the HIV Care Specialization program by serving as preceptors and teaching classes on women, children, and adolescents affected by HIV.

Left to right: Andrea Norberg, executive director, FXB Center; John Nelson, program director, AETC National Coordinating Resource Center, FXB Center; and Peter Oates, adult nurse practitioner and director, health care services, FXB clinic

our students the skills to offer top-quality care," says Willard. Strong support for this plan came from William Holzemer, dean of the School of Nursing, whose

> 1 in 7 ARE UNAWARE THEY HAVE HIV



HIV-related research includes symptom management, stigma, and quality of life, and has earned him international distinction.

In partnership with its François-Xavier Bagnoud (FXB) Center, the School of Nursing applied for AETC program funding to launch a nurse practitioner HIV care education program. The application was successful and the School of Nursing was one of four nursing institutions to be awarded the grant in 2013. It is the only one of these schools to offer HIV specialization as part of a DNP program.

Innovations in Teaching

"C aring for people with HIV is the most rewarding thing I've ever done as a nurse," says Darcel Reyes, clinical instructor and associate director of the HIV Care Specialization program. "My patients have made me realize just how vital our work is."

She joined the School of Nursing in 2014 to help build the HIV program's curriculum. With outstanding credentials, she's another in a long line of nursing professionals who bring extensive HIV experience into the classroom.

"Nursing curriculum is greatly influenced by accreditation and

and Diagnosis, Care and Treatment for Primary Care Providers.

The HIV care program builds on the curricula for primary care providers that includes adult gerontology, family, psychiatric/ mental health, and pediatric nurse practitioners. "Many students who have not selected the HIV specialization track are inspired to pursue it after taking the Social Determinants course," says Reves.

She adds that HIV specialization has a strong focus on primary care. "You're treating many other conditions besides HIV. So you must understand how HIV interacts with

"HIV is clinically challenging, so as a clinician, you don't just follow the dots. Providing the best care requires strong critical thinking skills."

licensure demands, so HIV content is often lacking or outdated," says Reyes. The AETC grant presented the opportunity to develop a new core curriculum of three courses: Social Determinants of Health and the Impact on HIV Care; Responses to the HIV Epidemic; diabetes, hypertension, and other health problems."

Reyes takes an experiential approach to teaching. In one exercise, students go on an HIV 'medication regimen' (substituting TicTacs for pills) for a semester to understand the challenges of



adherence. Some take a single pill while others take several. Another exercise is modeled after a clinicians warmline that consults on HIV clinical management. "I call students with a problem they must figure out," says Reyes. "I use my own real-life examples." She invites guest lecturers to speak on many topics, including health policy, adolescent care, mental health, substance abuse, oral health, and living with HIV.

Another teaching tool is the new national HIV curriculum. School of Nursing faculty member John Nelson was instrumental in establishing this free online program, a part of AETC. "We need these tools and more," says Reyes. "This field changes rapidly. There are new medications, new theories on viral load. Our graduates will have this current knowledge."



Left to right: Instructor Darcel Reyes with students Samantha Anderson and Kelly Schoch

"Nursing education should serve as a platform for continued lifelong learning and should include opportunities for seamless transition to higher degree programs."

FROM "THE FUTURE OF NURSING" BY THE INSTITUTE OF MEDICINE, OCTOBER 2010

Time in the Field

"Tell me and I forget, teach me and I may remember, involve me and I learn." | BENJAMIN FRANKLIN

Nurse practitioner Nancy Scangarello remembers the first days of the HIV epidemic in Newark, NJ. It was the early 1980s and she was providing critical care at St. Michael's Medical Center in Newark, where she still works.

"So many young men came in with PCP pneumonia," she recalls. "It was a mystery, and constantly evolving. Every day was a learning experience." Scangarello has spent a career caring for patients with HIV. She shares her knowledge by serving as a preceptor for the School of Nursing's HIV Care Specialization program. Students do 135 hours of clinical rotations each semester at HIV treatment sites throughout the state, supervised by preceptors. St. Michael's, long known for its work in infectious diseases, treats some 1,000 individuals with HIV at the

A preceptorship gives student Uchechi Esochaghi hands-on experience providing HIV care in a clinical setting, under the careful supervision of nurse practitioner Nancy Scangarello.

Peter Ho Memorial Clinic.

Under Scangarello's supervision DNP student Uchechi Esochaghi is doing her first clinical rotation. "Many people with HIV don't know much about prevention and new treatments," she says. "I want to be involved in preventing the spread of this disease, and getting people diagnosed and into treatment if they have it." She chose the Rutgers DNP program because it offers HIV specialization.

"Students first shadow me, then transition to taking histories and doing examinations," explains Scangarello. "Gradually they move to the next step: preparing treatment plans. Along the way I observe and offer feedback."

"Nancy listens to my suggestions and gives input that helps me come up with the best course of treatment for each patient," says Esochaghi. "I'm learning so much from her."

Familiarizing students with the

priority. "The list is overwhelming,"

help, I bring in pharmaceutical reps

from companies making HIV medi-

cations to speak to the students."

Scangarello explains. "For expert

myriad of HIV medications is a

These lessons are invaluable, says Esochaghi. "We learn about the medications in pharmacology class, but the information from the

"Preceptorship bridges the gap between the classroom and clinical care, allowing me to share what I know with this next generation of nurses." ADVANCED PRACTICE NURSE AND PRECEPTOR NANCY SCANGARELLO

> reps adds a new dimension about interactions, viral loads, resistance to medications, and other issues." Scangarello describes other facets of HIV care students need to learn: addressing substance abuse, comorbidities, even health



What is health care delivery like far across the globe, in Tanzania? To answer the question and provide interested students with a global



health experience, the School of Nursing launched a study abroad program in this African country, where students, faculty and staff meet with students, tour a hospital, and visit an HIV clinic to witness the care provided. The project is part of the Global Health Practicum course, a nursing elective sponsored by the school's Center for Global Health.



insurance issues. "I tell students not to try and do everything themselves," says Scangarello. "This is a team effort. If a patient has a mental health need, don't hesitate to make that referral to our mental health counselor."

Esochaghi is Nigerian, so it's not surprising that her career goals are focused on global medicine. This past spring she had the opportunity to go on the School of Nursing's study abroad trip to Tanzania.

"I was inspired by the dedication of the HIV professionals I met in Africa," she says. "While they have deep clinical knowledge, they lack the supplies and equipment we have in the U.S. When my training is finished, it's my dream to go to Nigeria and work with HIV patients. I want to make a difference."

Clinical Training Sites

Students in the School of Nursing's Advanced Practice HIV Care Specialization program receive clinical training at sites throughout the state.

- 1. North Jersey Community Research Initiative (Newark)
- 2. African American Office of Gay Concerns (Newark)
- 3. Peter Ho Memorial Clinic at St. Michael's Medical Center (Newark)
- 4. Visiting Nurses Association Health Group (statewide)
- 5. Smith Center for Infectious Diseases and Urban Health (East Orange)
- 6. Newark Beth Israel Medical Center: Family Treatment Center (Newark)
- 7. Jersey Shore Medical Center HIV & AIDS Ambulatory Care Clinic (A-Team) (Neptune City)
- 8. Infectious Disease Associates at Atlanticare Regional Medical Center (Atlantic City)
- 9. Cooper Hospital Infectious Diseases (Camden)
- 10. Raritan Bay Medical Center (Perth Amboy)
- 11. Hackensack University Medical Center (Hackensack)
- 12. Broadway House (Newark)
- 13. Jersey City Comprehensive Care (Jersey City)
- 14. Garden State Infectious Disease Associates (Voorhees)
- 15. Henry J. Austin Health Center (Trenton)
- 16. Infectious Disease Care (Hillsborough)

Living with HIV

Through a compelling threehour lecture he delivers to students in the HIV education program each semester, Adam Thompson shares his experiences as a person living with HIV.

Thompson learned he had HIV in a very public way. As he left the clinic where he was tested, the receptionist called out into the crowded waiting room: "Be sure to follow up at the health department with your HIV diagnosis." The room went silent as everyone looked at him.

That was in 2005, but the stigma of AIDS persists, preventing HIV services from reaching the people who need them. "I'm fortunate to have been diagnosed and treated within the first year of becoming infected," says Thompson. "I'm on a regimen of medication that's keeping me healthy, but others are not so fortunate." As the AETC regional partner director of the South Jersey Local Performance Site at Kennedy Health Alliance. he's an expert in HIV health care training and quality. He became involved with the School of Nursing when Kennedy Health Alliance became a training site. "Sue Willard heard my story and asked me to give the students my perspective on living with HIV," he says.



Growing up in West Virginia, Thompson knew he was different, but hadn't yet realized he was gay. Attending Georgetown University, he felt "out of water—a small town boy with a twang." In college he came to grips with his sexuality and worked hard to succeed academically, also working long hours to earn enough money to sustain living in the city.

On the eve of graduation Thompson learned he lacked three courses he needed. Devastated, he left college. Somewhat adrift, he began exploring gay bars and websites. "Many of the men I met used drugs and I became swept up in that lifestyle," he says. "A year later, I'm homeless, a sex worker, a drug user, and infected with HIV."

He turned to a fraternity brother who was now a resident physician.

"He saved my life and got me into care," he says. As Thompson recovered he began his public health career as an outreach worker targeting gay men on the internet. Over time he moved to higher-level positions, building a career devoted to advocating and improving and transforming HIV service delivery, capacity, and quality management.

"I was probably that clinic's first HIV patient," he says. "It wasn't that they gave bad care; they simply didn't have the capacity to manage this. I didn't want other people to go through this experience.

"Treatment is free, but people come for one visit and don't return," he continues. Health care providers have to find ways to build trust and get people into care."



Education Prevents HIV

Shaakira Abdul Razzaq completed her doctorate in nursing practice in the spring of 2017 and plans a career working among urban populations with significant risks.

"HIV is prevalent in the African American community and this is the population I want to serve," she says. She was drawn to the Rutgers HIV program because of its clinical orientation. Students can add the HIV care specialization to whatever clinical advanced practice nursing program they select. Abdul Razzaq chose the Family Nurse Practitioner track.

"The clinical component of this program helps me understand my patients," she says. "Many of them have social issues. They are underserved, mostly young, minorities, gay, and transsexual. It's a complex group of patients. You can't just treat the symptoms: you have to treat the patient holistically, connect with them, and gain their trust."

She has a special interest in reaching and educating young Muslims. As a nursing student she became a single mother, going against the teachings of the Quran, which, she explains, forbids premarital sex. Fortunately she had the family support that enabled her to continue her education without interruption.

"Many young Muslims are sexually active, but there is little sex education in this community," she says. "I want to address this need." She worked with other DNP students on "Sex Education in the Mosque," an abstinence-based approach to prevent HIV, STDs, and pregnancy. The curriculum is specifically geared to Muslims.

Abdul Razzaq has launched a nonprofit organization, Love Beyond Love, to spread the message, bringing workshops to mosques throughout the tri-state area. "I want to give young people the information and confidence to make informed decisions," she says. "Knowledge is the best protection against HIV."

Looking to the Future

With funding from HRSA, and through collaboration with our clinical partners, the School of Nursing has established a sustainable, successful Advanced Practice HIV Care Specialization program. Our graduates are making a difference in New Jersey and beyond:

- Managing the full spectrum of primary health care needs of HIV infected adults and adolescents, including mental health and substance abuse issues
- Providing HIV prevention methods in routine practice
- Building care programs in minority, inner-city communities
- Serving as educators and advocates across all sectors of society
- **Providing HIV prevention services** for high-risk individuals through pre-exposure prophylaxis (PrEP) programs
- Playing a role in global health and research, including clinical trials, vaccine and blood bank studies, and more
- Helping advocate and influence health policy to benefit others who lack a voice

Keeping pace with the challenges of HIV, our mission remains the same: ensuring the next generation will offer competent, compassionate care for individuals affected by HIV.

RUTGERS School of Nursing

School of Nursing Rutgers, The State University of New Jersey Ackerson Hall 180 University Avenue Newark, NJ 07102

Phone: 973-972-3067

nursing.rutgers.edu nursing.rutgers.edu/HIV-care

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