Care & Prevention

Four Comprehensive Care Clinics break barriers to provide a continuum of care for people with HIV and AIDS in Vermont

Cover story by Sarah Long • Photo by Jay Wiley

As HIV treatments have progressed and deaths among people with AIDS have decreased, the focus of HIV/AIDS nursing has shifted from caring for patients as they die to helping patients live with a chronic disease.

"Certainly in the beginning of the epidemic we didn't know anything, and we got good at helping people die," said Deborah Kutzko, APRN, ACRN, infectious disease nurse practitioner at Fletcher Allen Health Care, Burlington, VT.

When HIV was first identified in the U.S. in 1981, it took several years for scientists to develop a test for the virus, to understand how HIV was transmitted between humans, and to determine what people could do to protect themselves.

During the mid-to-late 1990s, advances in HIV treatments slowed the progression of HIV infection to AIDS and led to dramatic decreases in deaths among people with AIDS living in the U.S., according to the CDC.

"It's been truly exciting to have all these new medications and watch people go back to life," Kutkzo said. "And in fact people with HIV now live a pretty normal life. It's just another chronic disease, whereas in the beginning we had a hospice nurse as a permanent member of our team. We don't need that anymore."

Comprehensive Care Clinics

Kutzko is a nurse practitioner coordinator at the Comprehensive Care Clinic (CCC) at Fletcher Allen Health Care, one of four statewide HIV clinics serving the state of Vermont. The Burlington CCC was established in 1987. The Rutland, Brattleboro and St. Johnsbury CCCs were established in 1994, 1995 and 1996 respectively.

The clinics were established to overcome barriers to providing a continuum of care for people with HIV infection in rural Vermont, including long travel distances to receive state-of-the-art healthcare, long harsh winters, limited public transportation, concern about confidentiality in small towns, and limited HIV expertise among regional providers.

The CCC provides HIV care and case management to 381 active patients across the state, 260 of whom are treated in Burlington.

Indeed, the CCC has made great strides in serving rural populations with HIV, said Peter Jacobsen, executive director of Burlington-based Vermont CARES, the largest and longest-serving AIDS service organization in the state.

"Their clinic network allows limited staff to serve many people in a holistic manner," Jacobsen said. "By working hand-in-hand with social service providers and AIDS service organizations, the CCC is actively reducing barriers to care."

Declining Numbers

The Vermont Department of Health funds AIDS service organizations like Vermont CARES for case management and works with the CCC in referring clients and getting emergency service help, said Rob Lunn, MPA, the department's AIDS director.

"The CCC also collaborates with us on HIV trainings we do, and we often work with them on surveillance issues, HIV testing and other training issues," he said. "In our small state, we are faced with minimal funding that often gets stretched thin. We all work collaboratively the best we can to provide a level of service and prevention activities on limited resources."

As of December 2007, the total number of Vermont residents known to be living with HIV was 243, and people living with AIDS was estimated at 241, Lunn said. (The prevalence rate among Vermonters was 38.9 per 100,000 people, based on 2006 population estimates, whereas the prevalence rate for the U.S. was 143 per 100,000.)

The total number of new HIV and AIDS diagnoses in Vermont continues to decrease, Lunn said. "Few deaths occur each year in Vermont where HIV is listed as an underlying cause of death."

Annual AIDS incidence in Vermont peaked in 1993 when 54 cases were diagnosed. After 1996, when new antiviral drugs resulted in a decline in new AIDS cases nationwide, an average of 10-12 cases have been diagnosed each year in Vermont. The reduction in new cases demonstrates the success of new treatments, both in Vermont and nationwide, Lunn said.

"People are living longer with HIV without developing AIDS. This speaks to the importance of continued focus on HIV prevention and HIV-related medical care in spite of declining statistics," he said.

Providing Care

The CCC provides primary and infectious disease specialty care for people with HIV disease. Each clinic is housed in a regional hospital or hospital outpatient clinic.

CARE CLOSE TO HOME: For the hundreds of people living with HIV/AIDS in Vermont, care is never too far away thanks to four Comprehensive Care Clinics. At the clinic at Brattleboro Memorial Hospital, Brattleboro, VT, Deborah Jones, FNP, AACRN, CNM, nurse practitioner, tests patient Freemona Roundtree. Other clinics are based in St. Johnsbury, Rutland and at Fletcher Allen Health Care in Burlington.

The Burlington clinic, which cares for the majority of patients, is staffed by a nurse practitioner and psychiatric nurse practitioner, five infectious disease physicians, a social worker, dietitian and support staff. The three other clinics are similarly staffed except an infectious disease physician, dietitian and psychiatric NP travel to those clinics on a regular basis.

Patients are evaluated for drug and alcohol abuse and psychiatric illness, and referrals are made for assessment and management. Clinic team members are active in hospice care and family support.

Looking back on the early days in the clinics, the medical community was losing patients frequently, said family nurse practitioner Deborah Jones, FNP, AACRN, CNM, who runs the Brattleboro CCC, which serves 60 patients.

"It's a whole different thing now," she said. "In the time I've been here, I haven't lost a patient. I feel really fortunate I have to think about people living, not dying. It's not an easy disease to have, but we're doing a lot better. Twenty years out, and more patients are still surviving. It's big if we catch people early.

"You can slow progression to AIDS in the early days of the disease," Jones said. "They still may never have to progress to AIDS."

Weapons Available

The CCC provides a complete continuum of medical care, from immunizations, vaccinations and prophylaxis, to CD4 counts, viral load testing and antiretroviral therapy.

Counts of CD4, which are a certain type of white blood cell which fights infection in the body, indicate the strength of the immune system, how far HIV disease has advanced, and helps predict the risk of complications and debilitating infections. The CD4 count is most useful when it is compared with the count obtained from an earlier test. It is used in combination with the viral load test, which measures the level of HIV in the blood, to determine the staging and outlook of the disease.

Normal CD4 counts in adults range from 500 to 1,500 cells per cubic millimeter of blood. According to public health guidelines, preventive therapy should be started when an HIV-positive person, who has no symptoms, registers a CD4 count under 200.

The main drug treatment for people with HIV is highly active antiretroviral therapy (also called HAART), which helps to slow the growth of HIV in the body, according to the FDA.

First approved in 1995, HAART is made up of different kinds of medicines and the combined drug "cocktail" has changed AIDS from being an automatic death sentence to what is now often a chronic, but manageable, disease.

HIV/AIDS work is exciting because it's a wide-open field that is still being studied, Jones said.

"There are still things in the pipeline," she said. "Researchers are getting more effective working on a lot of things, such as a vaccine."

Overcoming Challenges

Kutzko has been in HIV nursing since 1984 and with the CCC since its inception. In the past 15 years, she saw options for patients increase from one clinic in Burlington, VT, and one in New Hampshire to four strategically located clinics throughout the state of Vermont.

"From the southern part of the state, we had people traveling 1½ or 2 hours up here to get care. It was always a problem. Someone with severe diarrhea who had to travel 2 hours, either they would have to travel up or we would try to do it over the phone, it never worked," she said. "So now we have these four clinics, everybody is within 45 minutes of a clinic. It makes it much better."

However, challenges still exist.

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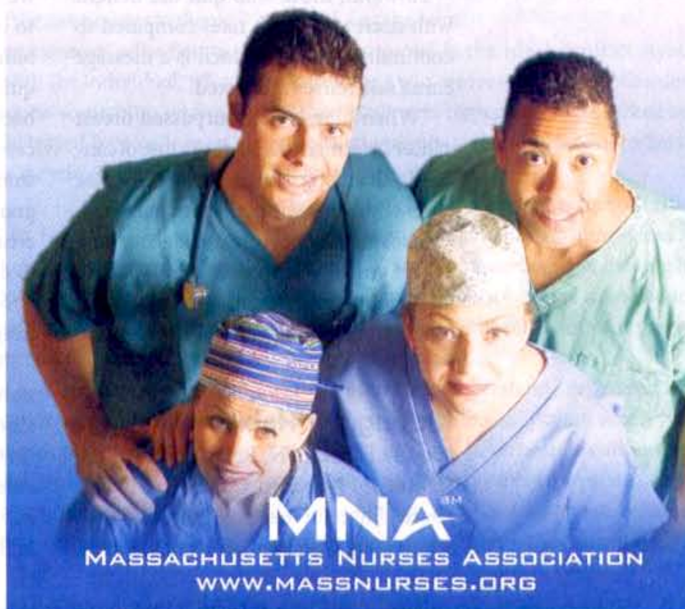

Q&A

Time Management

Promoting involvement on staff committees shouldn't compromise patient safety

Q: My hospital is implementing more nurse involvement throughout different levels, and RNs are being asked to participate on committees and attend meetings during their shift. This year I will have to attend three different committees each month, and I am concerned this will put an unfair burden on the other nurses who have to cover for my patients while I'm at meetings. Most of the meetings will be 1 hour, but one is asking for 2 hours during our 12-hour shifts.

I also worry about patient safety being compromised. What have other nurses at hospitals that have implemented committees done to deal with these issues, and what are some special arrangements they can recommend?

A: I work in a rural hospital in the operating room; therefore, we work 8-hour shifts. Nurses are encouraged to join committees to be part of the greater picture. Having said that, there are few volunteers for these committees, usually the same nurses each time a committee gathers.

There are nurses who would rather cover for staff nurses than join a committee, which helps balance out the staffing issues. Most nurses, who are doing patient care, join committees that are exclusively nursing focused. This makes it easier for planning ahead.

Most of the meetings are held in the late afternoon. For example, Clinical Ladder and Nurse Practice Council all meet typically from 4-6 p.m. Nurses who want to participate in committees are willing to come in during off hours to do so.

Our nurse manager encourages involvement and finds coverage if needed, or she will cover the nurse herself to allow participation for her staff, assuming it doesn't interfere with patient care.

If nurses want to become more involved, sometimes we need to work a little extra to allow those nurses to become more involved.

— Debbie Beauchesne, BS, RN, CNOR

Debbie Beauchesne is coordinator for orthopedic surgery at North Country Health Systems, Newport, VT.

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It's hard to convince some medical professionals, for example, HIV is a problem in rural areas just like anywhere else, Kutzko said. The Vermont Department of Health estimates, at the end of 2007, there were an estimated 153 to 179 residents who were living with the virus but had not been diagnosed.

"The problem we have is convincing medical providers to do HIV tests on their patients," she said. "Everybody needs to be tested. We see a lot of people who we can help have normal lives but if they don't get tested, and they come in when they're sick, then we can't do that."

The CDC suggests everyone between the ages of 16 and 64 get an HIV test, a guideline with which Kutzko wholeheartedly agrees.

"If you know you've got HIV, you're less likely to transmit it to other people, and you're more likely to take care of your own life," she said. "Everyone should know."

Rural Pros & Cons

Confidentiality can also be an issue in a rural area, Kutzko said.

"I think no matter what your disease is, confidentiality is an issue, but particularly with HIV, there is certainly still a stigma," she said. "We have patients who live in one area and get their care in a different area. Confidentiality is of paramount importance to us. We go through a lot to make sure none of that is ever breached."

Despite the challenges, however, one thing Vermont patients can count on is personalized care.

"I know each and every one of my patients well, and the other NPs know all of their patients," Kutzko said. "We are able to access services much easier here because it's smaller and there isn't as much bureaucracy."

The same goes for networking with other medical professionals and service organizations.

"We work closely with the state Department of Health and the local AIDS organizations. Again, the nice thing about being in Vermont is there just aren't many people," Kutzko said. "It's easy to make linkages and work cooperatively with other groups. Most of the prevention and outreach are done by the AIDS service organizations. But we support them in that and when they find people who are HIV-positive, they send them to us." ■

Sarah Long is a frequent contributor to *ADVANCE*.

FILTERING

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and skills in delivering smoking-cessation interventions to patients.

She also highly recommends nurses who want to quit smoking or to better serve their patients visit a Web site, [www.tobaccofreenurses.org], which provides a library of articles about smoking and smoking cessation, along with tools and resources to help nurses and student nurses help their patients stop smoking.

Ripple Effect

Sarna said patients benefit as nurses stop their own tobacco use.

"Although this study doesn't tell us the impact that nurses who are smokers have on helping patients quit, other studies have shown smoking status of healthcare providers does impact their smoking-cessation efforts for their patients," she said. "Healthcare providers who are smokers are less likely to intervene with patients who smoke."

Folan was pleasantly surprised when she took a close look at data from her smoking-cessation offerings. "About half of the nurses who quit smoking through our programs tell us they're breathing easier, coughing less or have a better sense of smell," she said.

"But about 75 percent of them tell us they no longer have a tobacco odor. 'Before, when I was at the bedside talking with patients about smoking cessation, I felt too guilty,' they'd tell me. Now, when they go in smoke-free, they feel more confident and are better educators and advocates for their patients who want to quit."

Johnson agreed. "We see a real ripple effect from our smoking-cessation community health programs," she said. "When we teach nurses to run these programs, they teach their colleagues as well as their patients, and do a better job of that teaching. They share positive messages about our smoking-cessation class, and that word-of-mouth encourages others to quit."

Folan is especially pleased when staff members tell her how tobacco-cessation programs have changed their lives.

"Nurses and other employees tell us they probably would not have quit smoking for many years to come if we hadn't offered this free and convenient program at their workplace," she said, adding the younger a person is when she quits smoking the better.

"The employees we see in our programs are much younger than the general population in our smoking-cessation classes," she said, "so we know we're helping them quit at a younger age, when the impact [of smoking] on their health is not as great." ■

Sandy Keefe is a frequent contributor to *ADVANCE*.