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New Grant Looks At Coping With Stigma of Rural HIV

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With a \$3.2 million grant, Sondra Solomon and Carol Miller have secured rare recognition of the problem of HIV/AIDS among rural populations. (Photo: Sally McCay)

Headed up the highway on a 60-mile roundtrip from his home in a small Vermont town, Jonathan Heinz is on a weekly run to pick up the multiple drugs he needs to manage HIV. He's been infected since the early 1980s, before these meds existed; he has no idea why he, unlike so many of his friends from the time, is still alive.

"I was told to get my affairs in order," Heinz says from his cell phone, "an easy job for me at the time. I had a few pairs of sneakers and some underwear. But I'm still alive."

Now sober, married, a homeowner, things are better but not easy, living on disability and dealing with the physical and emotional complications of having HIV. What's surprising about this drive is that there is a large chain drugstore in

Heinz's town. They stopped carrying his medications, a decision he was informed of carelessly in line in front of his small-town neighbors.

It might seem counterintuitive but Heinz is more comfortable making the long drive to a "mom-and-pop" pharmacy where the owners are friendly and give him a heads-up if he's running out of refills. He feels such places want the business and so they bother to educate themselves.

"It's surprising who can treat this with dignity and clarity," he says. "Some people you think can't, can, and some people you think can, don't. It's an amazing thing. You never know where stigma is or comes from."

And that — understanding stigma as an attribute that conveys a devalued social identity — is the driving force behind the work of psychology professors Sondra Solomon and Carol Miller, who were recently awarded a \$3.2 million five-year continuation grant from the National Institute of Mental Health for their research on coping strategies, sexual risk, and HIV stigma in rural communities.

Even in Kansas (or Killington)

The original \$1.5 million grant application was initially denied on the grounds that it would be impossible to recruit enough participants with HIV/AIDS in a rural state like Vermont. The team quickly signed up half of the 200 people in that study and easily got funding. The next phase will follow 250 subjects over a period of years.

"The thinking is that we don't have a big problem up here and we do," says Solomon. "People view HIV as an illness that happens only in big cities."

The official numbers for the state as of 2007, which captures only those who tested positive after 2000, are 217 people living with HIV and 234 living with AIDS. Those tested prior to the legislative reporting requirement, those tested in other states before moving to Vermont, and those who are positive but have never been tested, raise the number, Solomon estimates, closer to 800 at a minimum.

What interests Miller, Solomon, and their team is how these people cope and the impact their particular coping style has on their perception of stigma and on potentially risky sexual behavior. They do know stigma exists. A little less than half of the people surveyed indicated that something stigmatizing happened to them every day; on average, survey participants said they experienced stigma three times per week. The actual incidences of discrimination reported, however, were far fewer than people feared.

Another key piece of the study looks at social pressure within communities to control prejudice against people with HIV/AIDS. The desire to fit in, researchers believe, is a stronger indicator of behavior than people's actual inner

prejudice.

One surprise in the initial findings was where impetus to control prejudice was likely — or not — to occur. "We were expecting," says Miller, "that there might be a relationship between whether or not people thought it was OK to be prejudiced and the size of the community. We didn't find that. You can't just say there's more stigma in rural areas and less in more urban areas like Burlington."

Power to cope

Erasing prejudice and stigmatization would be ideal, but in the real world the research shows that coping styles are the most determinative in terms of both emotional wellbeing and likelihood of engaging in safe or risky behaviors, such as consistency of condom use.

People with HIV/AIDS roughly fall into two groups: engagement and disengagement copers. The former are more likely to problem-solve, act proactively, join support groups; the latter to avoid, which might include anything from self-denial of the problem, failure to disclose to potential sexual partners, or even to seek medical care.

Two key findings from the team's initial study verify that engagement coping leads to better outcomes. "The literature indicates that stigma creates problems for people," says Miller. "What we see is that there are certain ways of coping that will help alleviate those problems."

Conversely, in an upcoming paper in the *Journal of Health Psychology*, Solomon, Miller, and colleagues show that higher levels of disengagement coping are related to the greatest degrees of anxiety and depression symptoms. How actual and perceived stigma within communities relates to these outcomes is a primary question of the new research.

The work is still at the basic research stage but the hope is to eventually develop interventions. "If we know people are particularly avoidant," says Solomon, "we can address those coping strategies and try to reshape them, to empower people. And we can educate the community."

But for the many groups in Vermont who serve those living with HIV/AIDS, who Solomon says the research couldn't function without, the work is helping now.

"This directly bolsters our work in HIV advocacy and outreach," says Peter Jacobsen, executive director of Vermont CARES (Committee for AIDS Resources, Education & Services). "We've been partnering with Sondra and her research partners at UVM for years turning theory into practice. (She) has shared her perspectives and research around HIV stigma and helped us to better speak with those we serve about this persistent and confusing topic."

The need is here, for both the research and on-the-ground outreach. Jonathan Heinz makes it clear. "It's hard work to ensure I don't allow that toxic poison into my being, to not feed into what I think the world perception of me might be," he says. "I lose some battles. But I'm winning the war."