

HIV patients still stung by stigma from health-care providers

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The doctor who wouldn't come into the patient's hospital room. The neurologist who avoided eye contact. The ambulance attendant who angrily threw her bloodied gloves into the street after learning the injured patient was HIV-positive.

These are reactions of some health-care personnel when faced with caring for persons infected with the human immunodeficiency virus (HIV) more than 25 years after its discovery.

The experiences are documented in a study headed by Lance S. Rintamaki, Ph.D., an assistant professor of communication and health behavior in the College of Arts and Sciences at the University at Buffalo and published recently in the journal *AIDS Patient Care and STDs*.

"This study reveals the variety of such problematic events," said Rintamaki, "as well as the considerable array of health-care personnel listed by participants in this study. Clinicians should have the training and common sense to avoid a lot of these behaviors, but perhaps we shouldn't be surprised when hearing about nonclinical staff caught up in these events. They're likely relying on the same stereotypes and misinformation about HIV that are commonplace among the general public, which may lead them to act in fearful and stigmatizing ways toward HIV-positive patients."

Persons infected with HIV must spend considerable time in the presence of health-care personnel in dealing with their disease, and experiencing

stigma can be discouraging. They have labeled dealing with stigma the most significant social and psychological challenge of the HIV experience.

Rintamaki said the handful of existing studies of HIV stigma in health-care settings have focused mostly on one type of health-care personnel, such as doctors or nurses, and have documented their self-reported attitudes rather than the actual experiences of patients on the receiving end of those attitudes. Those few that have tried to document the frequency of such events have failed to describe the specific behaviors these events entail, he noted.

To take this next step, Rintamaki and colleagues recruited a convenience sample of 50 people seen in the infectious disease units of three Veterans Administration hospitals in the Midwest.

The study was conducted in phases. Eight of the volunteers explained their experiences with stigmatizing behavior in health-care settings in two focus groups. Researchers then incorporated these data into one-on-one recorded interviews with the remaining 42 participants.

Interviews were transcribed and experiences were coded and categorized by type of stigmatizing behavior that study participants experienced most often in the presence of health-care personnel. These categories were: lack of eye contact; assuming physical distance; using disdainful voice tone or inflection; asking confrontational questions; showing irritation, anger, nervousness, fear or panic; taking excessive precautions; scaring, mocking, blaming or ignoring patients; providing substandard care or denying care, and being generally abusive.

Several participants reported only positive experiences with health-care providers, while others reported experiencing stigma in a variety of health-care settings by a variety of providers.

One participant said he had so little eye contact with his neurologist that he couldn't describe the doctor's face, according to the study. Another participant recounted a nurse's disdain when she delivered his AIDS diagnosis: "It was just so callous and cold the way she said it... 'You have AIDS.'... There was no feeling. It's almost like a stone-faced warden or something. No concern."

Stigmatizing experiences included judgmental behavior and panic on the part of providers when informed of a patient's HIV status, doctors "hermetically sealing" themselves before approaching the patient and patients being told they were going to die.

Participants described being blamed openly by health-care providers for their condition. One patient told of being scolded by a phlebotomist -- "If you hadn't done this to yourself, we wouldn't have to be going through this!" -- when he objected to being "poked" painfully several times as she searched for a viable vein to draw blood.

Other reports included the hospital worker who refused to mop the floor in an HIV patient's hospital room, the dentist who turned away a patient because of his HIV status and rough-handling by paramedics.

"This study reveals that patients are sensitive to such behaviors, indicating the need for all health-care personnel to be mindful of their actions toward these patients," said Rintamaki.

"Given patients' sensitivity to any indication of bias or discrimination, it's likely that even well-intentioned health-care personnel sometimes engage in behaviors that are interpreted negatively by their patients. The findings from this study give health-care personnel additional insights on what to avoid, or if certain protocols are standard procedure, what to explain further. These approaches might help to prevent misunderstandings and hard feelings."

Source: University at Buffalo

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