

Adults with HIV who have compassionate care providers start and remain in treatment longer

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Adults with HIV are more likely to continue life-saving treatments if their primary health care providers show respect, unconditional empathy without judgement and demonstrate an ability to partner with patients in decision making to address their goals, a Rutgers study finds.

The [systematic review](#) appears in the *Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports*.

The findings showed that the complexity of the illness, treatment regimen and overall healthcare system frequently overwhelms the patient and fear of stigma often prevents them from beginning or continuing treatment. The researchers found that patients need help in understanding their illness and care needs using understandable language to translate complex information, letting patients know what to expect and reinforcing that HIV is now a treatable, yet complex, chronic illness.

"Today, HIV is considered a chronic, treatable condition. However, this study found that many patients continue to view it as a [death sentence](#)," said lead author Andrea Norberg, executive director of the François-Xavier Bagnoud Center at Rutgers School of Nursing, which provides care for people with HIV, infectious diseases and immunologic disorders. "We know that people who are knowledgeable about HIV, who are engaged in care and taking antiretroviral therapy medications remain relatively healthy. Our challenge is to reach those people

diagnosed with HIV and who are not retained or engaged in ongoing care. In the United States, this is approximately 49 percent of the 1.1 million people diagnosed."

The researchers included 41 studies published between 1997 to 2017. The sample populations included adults with HIV and their [healthcare providers](#). All adults with HIV were between the ages of 18 and 65, represented diverse races and ethnicities, sexual orientations and gender identities. Healthcare providers included physicians, nurse practitioners, physician assistants, pharmacists, social workers and others. The included studies had 1,597 participants.

They found that many patients experience stigma and a lack of compassion that is often grounded in primary care providers' ignorance about HIV and transmission risks. The resulting poor communication between providers and patients results in many patients' failure to seek or remain in care and adhere to antiretroviral therapy medications.

Patients reported feeling "grilled" by providers who often assumed they were not taking medications. Norberg suggested providers would be more successful in getting information from patients by allowing them to be honest, inquiring about their health goals and telling them how other patients have managed treatment.

Conversely, the researchers found that patients were more inclined to adhere to HIV treatment when their primary care providers showed empathy, true listening, trust, consideration of the whole person and involvement in decision making. However, many patients reported that healthcare providers viewed care only as "prescribing antiretroviral therapy medicine."

"Providers should use common language, not medical jargon, to educate patients about HIV, medications and how they can live a healthy life,"

Norberg said. "They should thoroughly teach them about the disease, the medications and side effects, and the meaning of the tests."

The researchers noted that providers who help patients navigate the health system, offer one-stop location of services and provide connections to psychological support, health insurance, medicine, transportation and other services, can help their patients stay engaged in care.

Primary healthcare providers can enroll in professional education to improve their knowledge about HIV, use of motivational interviewing skills and seek opportunities for experiential learning, observation and hands-on practice working directly with patients with HIV, Norberg said.

More information: Andrea Norberg et al, Experiences of HIV-infected adults and healthcare providers with healthcare delivery practices that influence engagement in US primary healthcare settings, *JBIR Database of Systematic Reviews and Implementation Reports* (2019). [DOI: 10.11124/JBISRIR-2017-003756](https://doi.org/10.11124/JBISRIR-2017-003756)

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