

# HIV Provider Perspectives: The Impact of Stigma on Substance Abusers Living with HIV in a Rural Area of the United States

John F. Yannessa, Ph.D.,<sup>1</sup> Michael Reece, Ph.D., M.P.H.,<sup>2</sup> and Tania B. Basta, Ph.D., M.P.H.<sup>3</sup>

## Abstract

Recent literature has documented growing concerns related to access to HIV care services for rural individuals living with both HIV and a dual diagnosis of substance abuse. Previous research has investigated issues from a client perspective, but limited research has investigated provider perspectives of rural issues surrounding HIV and substance abuse. The purpose of this qualitative study was to examine issues that impact the ability of care providers to create sustainable linkages to care for dual diagnosed individuals who live in rural areas. In-depth interviews were conducted in late 2005 with 39 HIV service providers at 11 agencies that provided HIV-related services to individuals in rural areas of a Midwestern state in the United States. Findings suggest multidimensional stigma in the medical referral network as the leading factor that presents challenges to service providers in rural areas. The service providers reported verbal stigma in the form of insults, a loss of role/respect, and a global loss of resources such as poorer quality health care or no health care provided. The stigma is conceptualized in four themes: (1) staff of medical referral sources stigmatizing against rural dual-diagnosis clients, (2) physicians stigmatizing against rural dual-diagnosis clients, (3) medical specialists stigmatizing against rural dual-diagnosis clients, and (4) client-perceived stigma. These themes were expressed equally among all of the providers, regardless of geographic location, type of HIV-related organization, or job title.

## Introduction

RECENT ESTIMATES by the Centers for Disease Control and Prevention (CDC) indicate that the number of people living with in the United States has surpassed 1 million.<sup>1</sup> Furthermore, it is estimated that approximately 40,000 people are newly infected with HIV each year in the United States.<sup>2</sup> Since HIV was first detected, incidence has remained high in urban areas of the country. As a result, HIV-related research has focused largely on individuals living in urban settings. However, over the past decade, HIV incidence has been increasing in more rural regions of the country.<sup>3</sup> Between 1991 and 1992, the number of rural AIDS cases increased nearly 10%, or nearly three times greater than the 3% increase in the urban areas.<sup>4</sup> Furthermore, by the end of 2004, more than 50,000 individuals were living in non-metropolitan statistical areas (MSAs) in the United States when they received an AIDS diagnosis, representing approximately 6% of all U.S. AIDS cases.<sup>5</sup> But despite these

data indicating that rural areas have suffered from a disproportionate increase in rate of HIV/AIDS infection, most rural areas lack services for residents living with HIV.<sup>6</sup>

Nearly three quarters of rural residents living with HIV seek care for their infection in urban areas.<sup>7</sup> The reasons for this rural-to-urban migration pattern are multifaceted. First, since the majority of individuals living with HIV reside in urban populations, the development of a comprehensive HIV treatment infrastructure has been focused in these areas and there has been more limited development of sufficient HIV-related programs in rural areas. To this end, many rural individuals report having to travel long distances to urban areas in order to receive HIV-related care services, which can be further complicated by the lack of public transportation available in rural areas.<sup>8</sup> Other research indicates that people living with HIV in rural areas travel to metropolitan areas for medical care due to concerns about confidentiality, or lack of confidence in the ability of rural physicians to assist in the medical management of HIV infection.<sup>9</sup>

<sup>1</sup>Coastal Carolina University, Department of Health, Kinesiology and Sports Studies, Conway, South Carolina.

<sup>2</sup>Indiana University, Department of Applied Health Science, Bloomington, Indiana.

<sup>3</sup>Ohio University, School of Health Sciences, Athens, Ohio.

Researchers have also reported that rural residents living with HIV are challenged by a lack of adequately trained medical and mental health providers.<sup>8</sup>

It has been recognized for quite some time that certain illnesses or conditions are associated with an increased level of stigma,<sup>10</sup> including: lung cancer,<sup>11</sup> sexually transmitted infections,<sup>12</sup> and HIV/AIDS.<sup>13</sup> Past researchers have defined stigma as a process by which individuals living with a devalued physical condition often experience prejudice, discrimination, and stereotyping.<sup>13</sup> As recently as 1999, Herek and colleagues<sup>14</sup> suggested that nearly 1 in 5 Americans surveyed admitted fearing persons living with HIV/AIDS. Although the HIV epidemic has been in existence for nearly 30 years, and despite nearly a quarter century of public education about HIV, stigma associated with the infection continues to be a major public health issue.<sup>15,16</sup>

A recent study by Kinsler and colleagues<sup>17</sup> found that 25% of individuals living with HIV/AIDS experienced perceived stigma from a health care provider at baseline and 20% reported the same perception 6 months later. Furthermore, those with higher levels of perceived stigma were less likely to access care services. While this study was conducted in an urban setting, it adds another dimension to health care access in rural individuals living with HIV.

Much of the literature related to rural HIV care focuses on the perspectives of the person living with HIV.<sup>8,18</sup> There is little published research about the challenges faced by rural HIV care providers. Our review identified only two studies in which the purpose was to assess provider perceptions of challenges to care delivery.<sup>19,20</sup> To that end, there appears to be little published evidence of challenges rural care providers encounter when trying to link their rural clients to HIV-related care and other health-related services. In particular, the limited HIV specific infrastructure may be particularly challenging for individuals facing the additional stigmas associated with a dual diagnosis of HIV and a mental health issue or substance abuse.

Both mental health issues and substance abuse have been well documented as being prevalent among individuals living with HIV. Such dual diagnosis has been documented to occur at significant rates, with 47% of persons living with HIV also facing a mental health issue and 13% facing challenges associated with substance abuse.<sup>21</sup> In addition to substance abuse, mental health challenges to those living with HIV infection have been described as being prevalent, particularly with regard to depression and adjustment disorder, but the nature and intensity of such psychological challenges are known to vary greatly in terms of nature and intensity over the course of infection.<sup>22-29</sup> Additionally, the dual impact of HIV infection and mental health challenges or substance use disorders has been well documented as being associated with negative care outcomes, including increased morbidity, less adherence with medical treatment and medications, and less engagement with the HIV care system.<sup>30-39</sup>

As a result, it is imperative that those in the HIV care infrastructure have the appropriate mechanisms to address both the primary care needs of individuals living with HIV and the other mental health and substance abuse issues of those with a dual diagnosis. Given that rural areas continue to have less developed infrastructures for responding to HIV, an understanding of the challenges that these providers face

when attempting to link their individuals to these services may provide valuable insights as the care infrastructures in these areas continue to develop.

The purpose of this study was to examine HIV providers' perspectives on: (1) client retention and outcomes, (2) challenges to effective counseling, (3) client social networks, and (4) the effectiveness of counseling and testing, and how these issues impact the ability of providers to create sustainable linkages to care sources for rural clients living with HIV and a dual diagnosis of substance abuse or a mental health issue.

## Methods

### *Participant recruitment*

All participants in this study were HIV service professionals who were providing care to individuals living with HIV from rural areas of a large Midwestern U.S. state. The providers recruited for this study served primarily as case managers or care coordinators for clients living with HIV. In all cases, providers offered their clients intensive case management and potential linkage to support services. Purposeful sampling of the state's HIV providers was conducted to derive an in-depth understanding of provider perspectives about challenges in providing care specifically to rural populations.<sup>40</sup> The study was designed to include a variety of HIV care providers in order to gain a perspective of both the challenges and successes to providing HIV-related care to individuals from rural areas. For readability, the participants in this study are referred to as "providers."

At each of the 15 HIV care coordination sites that form the infrastructure of the HIV care system in the state where this study was conducted, program managers were contacted and asked to provide a list of the core staff members of their agencies. Each provider was subsequently contacted via phone to describe the study and, for those interested in participation, to schedule an interview. Of the 42 providers contacted, 93% agreed to participate.

Data were collected in late 2005 from 39 HIV service providers in the 15 HIV-related care programs throughout the state. These sites varied in size, geography, and ethnic-cultural composition of clients they served.

### *Data collection and measures*

The data collection process consisted of conducting semi-structured interviews, either in person or over the phone. In each case, the providers' identities were kept either confidential (name given, but coded) or anonymous (no name given). No specific demographic information was collected from the providers because they were concerned about confidentiality and the repercussions at work if their identities were revealed, although some data related to gender and ethnicity were revealed by providers during the course of the interviews. The providers included in this study included both men and women, and individuals from a variety of ethnic backgrounds including African American, Latino, and white. A majority of the providers (75%,  $n = 29$ ) who chose to participate in this study disclosed that they had served in their role for 5 or more years prior to the interview taking place.

While certain questions were asked of each of the

providers, a semistructured format was used in order to allow for probing among participants.<sup>40</sup> The semistructured interview guide included three core questions in each of four key areas, which asked providers to describe their perspectives related to: (1) client retention and client outcomes related to provision of care, (2) challenges to effective counseling–testing (or job focus as appropriate, such as case management), (3) access to client social networks, and (4) the effectiveness of current counseling and testing methods (or the methods of the job focus). The interviews lasted approximately 30 minutes and were audiotaped. Providers received no reimbursement for their participation. However, in accordance with human subject protocols, each provider was informed that he/she could voluntarily decline participation without penalty. All research and evaluation protocols were approved by the Institutional Review Board of Indiana University-Bloomington.

### *Data analyses*

Analysis occurred in several phases. First, all of the audiotapes were transcribed verbatim, identifiers were removed, and references to individuals were removed to preserve confidentiality. Then, using thematic analysis, the researchers reviewed the transcripts, and coded data related to HIV-related stigma.<sup>41</sup> The units of analysis were sentences, phrases, or paragraphs. These codes were organized into larger categories of responses. Next, these codes and responses were reviewed by four researchers. If discrepancies occurred, then differences were discussed and clarified until a consensus was reached that data had been coded into the most appropriate category. This process, conducted in an effort to reduce bias, and to obtain the richest possible data set,<sup>42</sup> resulted in 100% concordance among the researchers.

### **Results**

Results indicate that the health care providers in this study encountered multifaceted stigma when accessing the existing rural health care infrastructure in the effort to link their clients with existing services. Health care providers reported that their clients encountered verbal stigma (insults), loss of role (loss of respect), and a global loss of resources including poorer quality or no health care provided. This stigma and discrimination was described by participants as challenging their ability to access effective care for their rural clients facing dual diagnosis issues.

The stigma the providers described is best conceptualized in four themes: (1) staff of medical referral sources stigmatizing against rural dual-diagnosis clients, (2) physicians stigmatizing against rural dual-diagnosis clients, (3) medical specialists stigmatizing against rural dual-diagnosis clients, and (4) client-perceived stigma. The aforementioned themes were expressed equally among all of the providers, regardless of geographic location, type of HIV-related organization, or job title.

#### *Theme 1: Stigmatized/marginalized dual-diagnosis clients by referral sources*

Providers suggested that staff within various health referral sources continued to act as a barrier to effective care.

Data analysis revealed that although the health provider's agency was officially linked to a referral source, on an organizational level, many staff of the referred medical facility expressed indifference toward the referred client.

I think, probably the most challenging factor would be their acceptance (sic) to diversity, whether they're gay-friendly or not, HIV-AIDS friendly. Lots of the providers I refer to say right up front that they aren't gonna (sic) see my dual diagnosis clients even though they're supposed to . . .

We're always constantly scanning people—because we don't want to send someone somewhere to get help, and then they end up getting discriminated against in the process. It is always happening, so you gotta (sic) be careful.

When asked if these issues were related to specific referral sites, providers typically reported that stigmatized staff in medical facilities was widespread in the rural medical system. For some, the issue evolved into an expectation that although the referral source was officially open to treatment of dual diagnosis clients, the staff of the referral sources was not open to treating these specialized clients. Trying to overcome the stigmatizing behaviors of the rural medical providers were common daily challenges HIV-related service providers.

I don't like referring my clients there because . . . they're not treated with respect, they're not believed.

Hospitals (staff) make assumptions about our clients that I think are inaccurate . . . they don't really care about our people.

The way they are treated makes it a very difficult system for someone who's sick and beaten down all the time to have to deal with.

#### *Theme 2: Physician stigma*

Providers also reported that they frequently encountered stigma among rural physicians when accessing a client care linkage. They often reported that after referring a client to a rural physician care, the client later reported that adequate care was not provided. For example, clients in some rural communities were referred to primary care physicians for treatment issues secondary to their HIV infection. The health care providers reported that the physicians often then referred the individual living with HIV elsewhere for treatment.

For primary care physicians, there's no problem dealing and working with somebody with diabetes. But when it comes to HIV, the general concept is, "I know nothing about it, so you should see your specialist."

Additionally, the providers reported that some rural physicians did not allow dual-diagnosis clients to access their medical practice.

We continually work on increasing our list of available physicians, primary care physicians to send people to, and specialists to send people to. And there's some peo-

ple that just (say), "No, my practice is full." It's not that it's full; it's that they don't want to deal with HIV.

### *Theme 3: HIV stigma among medical specialists*

Providers reported that for those clients whom they were able to secure an appointment, either the HIV-related provider, or the primary care physician would attempt to refer the rural client for a more specialized form of care. However, providers reported that these referrals were typically no more successful in helping their clients avoid stigmatized referral sources. One provider reported that although there are rural physicians who specialize in infectious disease treatment, frequently these encounters resulted in either a refusal of care or physicians exhibiting stigmatizing comments and/or behavior toward the dual-diagnosis client.

It (stigma) happens when my man, the doctor, tries to refer my people in xxxx County (rural) . . . They don't want to deal with our people. They don't want to deal with their people that are positive.

I think the biggest factor in our area is educating our physicians. There's a lot of them who don't want to learn HIV. They saw it as a resident.

They (the specialist) don't have to deal with it anymore, and they don't want to learn anything about it. That's been a big issue. They'll turn you away . . . They don't even want to do that (see a dual diagnosis client). So that's an issue.

I think if you send a person for treatment for addiction services that can be an issue. If you have somebody's (a client) that HIV positive, who's gay or bisexual or transgender, he or she does not feel like they're welcome at the facilities. They can't talk about anything that really deals with them because if they do, nobody's going to talk to you.

The providers were further probed about the stigma they encountered. Data indicated that during a physician encounter, the physicians exhibited behavior intended to discourage future visits by the client.

Well, we have one (infectious disease) doctor, if you don't have money, or insurance, she will not see you. The other has actually told our people that HIV positive clients are boring, and he doesn't want to work with them. He's actually told them that to their faces. If you're healthy, he'll keep you. If you're sick, he won't have anything to do with you.

As a result, providers reported that much of their workday is consumed with finding specialists who are receptive to treating their dual diagnosis clients. Providers also reported during this time consuming process, they actually provided updated treatment information to the physician specialists regarding new forms of treatment for dual-diagnosis clients.

They're not even open to HIV care. And they use that (as a) cop out, that the treatment changes too quickly, and, "I can't stay up to date on it." We tell them about new treatment options, and they don't really wanna hear me.

The providers suggested that finding medical treatment for their clients may be related to the treatment philosophy of the physicians. Some specialists prefer to focus on preventing HIV infection among individuals who are not positive; rather than assisting the client with positive living.

Yeah . . . medical referrals don't want to deal with our people (people living in rural communities). They don't want to deal with their people that are positive. They just want to prevent.

### *Theme 4: Client-perceived stigma*

A final component that limits the ability of HIV care providers to effectively link their dual diagnosis clients to medical, social, or mental health services is that the clients themselves stigmatize the types of health services they need for effective management of their various medical conditions. As a result, the dual diagnosis clients are often not compliant with referrals. A mental health specialist reported:

I had a client that was referred to me. He wasn't sure he wanted to come in. So I started asking him about it. He said, "Well, they just said you're the mental health counselor. That term, mental health, I don't like that." I said, "Well, let me explain what that is." . . . he ended up not coming in because he was just like, no, like I'm not crazy. And I even told him, I said, "You know, 99% of the people I see aren't crazy. They just aren't seeing something they're struggling with. They're not able to get past it on their own. So I think there's a big stigma to it."

The providers reported that within the various communities served, it is very difficult for them to overcome the stigma clients associated with their families and friends. Some providers indicated that their clients face stigma from family members who lack a full understanding of HIV transmission.

[Client families or partners say] don't eat anything they cook; or, don't stand too close to them; you know . . . Something might get on you; but I use each opportunity as a chance to do some education. Let them know how this is transmitted, and a little bit of everything involved. It's just a chance I have to educate the family, because a lot of people are still ignorant, and not learning the skills.

. . . People still chastise and criticize and judge individuals that are HIV positive. It's already hard enough to come and say, "I'm an alcoholic, I'm a drug addict" but to say "I'm HIV positive?" That's why they don't return from testing . . . it's a disease that they think; most people in the community will say "this guy is homosexual." That's what their perception is (that it is a gay disease), that's what their beliefs are.

## **Discussion**

This study is one of the first to investigate provider perceptions of stigma related to the provision of care to individuals living with HIV in rural areas of the United States. Given that there has been little research examining the HIV

provider perceptions of stigmatized health care resources, these findings may provide new insights for HIV social service providers as well as raise important considerations as HIV service providers seek to provide care for their clients.

The existence of stigma within the various medical communities was a central tenet of this study. Therefore, this research may be somewhat unique in that it offers insight into the daily struggles that providers face when trying to link their dual diagnosis clients to various health care resources. Results presented in this research may indicate that providers face much more complex and intense stigma within the rural system of health care than has been previously realized.

Previous researchers have suggested that lack of knowledge regarding health issues and health behavior can lead the public to stigmatize those behaviors which they do not understand. Brown and colleagues<sup>43</sup> reported that stigmatization can lead to prejudicial thoughts, behaviors, or actions on the parts of health care providers, friends and family, and the community at large.<sup>44-46</sup> These earlier results are supported by this research, in that the participants in this study indicated that many rural medical providers did not understand the complexities of HIV infection or available treatments, and also characterized a medical community endemic with prejudicial behaviors.

Additionally, these results support the previous findings of Reif and colleagues,<sup>19</sup> which identified HIV-related stigma to be a major issue related to medication adherence of the rural person living with HIV. Whereas those previous results identify stigma as an issue for the rural practitioner, it may be that the results in this investigation further our understanding of the extent to which rural medical communities still stigmatize HIV and those living with the virus.

Although the results of this research were expected, we were somewhat surprised by the extent to which the medical community stigmatizes rural dual-diagnosis clients. Given the volume of HIV educational material available to the medical community, one might link the availability of educational materials to possible increased HIV knowledge and subsequently more tolerant behavior toward those living with HIV.

It may be that the behavior of the medical community described in this study may relate to conservative cultural norms typically associated with the Midwestern United States. Past researchers have indicated that overcoming HIV-related stigma requires a modification of societal values about sex and drug use.<sup>47</sup> Because the participants in this study cared for dual diagnosis clients, some of the verbal and behavioral stigma the participants reported that their clients encountered may have been related to the clients sexual behaviors, drug use, or mental health issues. Therefore, these results may reveal the need for specific health promotion programs designed to reduce stigmas associated with behaviors ancillary to HIV exposure.

#### *Implications for practitioners and researchers*

Previous researchers have shown that HIV/AIDS stigma is expressed in many different ways.<sup>47,48</sup> During the last decade, there has been a declining trend of overt expressions of stigma among the adult public in the United States.<sup>14</sup> Additionally, these researchers indicated that many adults in

the United States felt uncomfortable having direct or symbolic contact with people living with HIV.<sup>14</sup> The results of this current study support the previous findings that many adults in the United States are uncomfortable associating with people living with HIV. We offer more specific conclusions, in that we suggest that adults employed in the medical community may also be uncomfortable associating with people living with HIV. In addition, findings from the present research highlight a particularly alarming issue that lies in contrast to previous research findings. Although overt expressions of stigmatized behaviors toward people living with HIV may be declining in general in the United States, our results indicate that these stigmatized behaviors may be unchanged in rural Indiana medical communities. Stigmatized behaviors by the associated medical community were routinely reported by the participants in this research. Participants reported that rural infectious disease physicians practiced overt stigmatizing behavior toward dual-diagnosis clients. Health professionals working with clients living with HIV may need to develop new educational strategies designed to reduce stigma in the various medical venues that clients access for care. An additional consideration may be enhancements to the policies that regulate the provision of HIV-related care in all areas such as including standardized assessments of substance abuse and mental health across all initial patient and client encounters when entering primary care or other federally funded HIV care and support programs. The implementation of such policies would also require that providers are trained in the administration of such assessments and that established referral protocols are mandatory for funded programs to ensure that clients are provided with appropriate referrals in an effective and non-stigmatizing manner.

#### *Limitations*

This study is not without limitations. The results reported in this study are from a small sample size. Qualitative research generates a large volume of data, and expanding the sample size would have been unmanageable.

The sample included a range of HIV-related providers, such as case managers, HIV education specialists, and mental health counselors. It could be that the identified issues are not fully represented by this sample. Future researchers may consider performing similar research with one identified cohort.

The challenges health care providers reported in this research should not be generalized to reflect the whole medical community. While this research supports the assertion that rural HIV stigma among rural HIV providers does exist, these results cannot be generalized beyond the study sample. The purpose of qualitative research is to gain a detailed understanding of a particular issue, but because purposeful sampling was used, and not random sampling, the results should not be considered indicative of all rural HIV-related health care providers in the state of Indiana.

#### *Directions for future research*

Necessary are prospective studies that explore mechanisms surrounding provider perceived stigma, and the behaviors employed by the care providers to overcome these professional barriers. For example, many of the practition-

ers in this sample described informal care networks they had developed in the effort to avoid those medical staff known to stigmatize their clients, yet still link their client to care effectively. It is important to clarify that informal care networks were not formal care networks with governance level relationships established. Rather, the informal networks refer to an informal networking process whose primary goal was circumventing the formal care networks and linking clients to care sources that were perceived as being minimally stigma laden. However, the long-term effectiveness of these informal networks is currently not known.

Recent research investigating rural HIV stigma has primarily been driven by a client perspective, and much of the research has focused on a quantitative design. Given that recent national and international organizations have called for a melding of quantitative and qualitative research regarding HIV-related stigma,<sup>49</sup> this research might offer future researchers insight regarding methodological considerations when attempting to investigate rural provider-based issues.

### Conclusion

It is our belief, and hope, that these study findings may promote dialogue among the medical community regarding provision of care to rural dual diagnosis individuals. Although it may be difficult for some in the medical community to accept that biased professionals are widespread, it may be increasingly important for health practitioners to lead discussion sessions with associated medical staff. These sessions should be characterized by frank dialogue in which the issues revealed in this research are discussed in depth, and opinions regarding dual diagnoses clients discussed. Such discussion may be an important step as health professionals seek to become more responsive to the physical, mental, social, and emotional needs of their clients.

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Address reprint requests to:

*John F. Yannessa, Ph.D.*

*Department of Health, Kinesiology and Sport Studies  
Spadoni College of Education  
Coastal Carolina University  
Conway, SC 29528-6054*

*E-mail: yannessa@coastal.edu*