Barriers to accessing HIV/AIDS care in North Carolina: Rural and urban differences

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Abstract

Many HIV-positive individuals face multiple barriers to care and therefore frequently experience unmet medical and support services needs. Rural areas often lack the infrastructure to support the delivery of comprehensive HIV services; however, few studies have examined service barriers faced by rural residents with HIV/AIDS, particularly in the South where two-thirds of people living with HIV/AIDS in rural areas reside. We surveyed North Carolina HIV/AIDS case managers (N = 111) employed at state-certified agencies regarding barriers to medical and support services that influence medication adherence for their rural and urban-living clients. For each of the seven barriers assessed (long travel for care, HIV-related stigma, and a lack of transportation; HIV-trained medical practitioners; housing; mental health services and substance abuse treatment), a substantial proportion of case managers (29–67%) reported it was a ‘major problem’. For five of the seven barriers, rural case managers were significantly more likely to identify the barrier as a ‘major problem’. Multivariate analysis revealed that rural case managers and case managers with more female clients reported a greater number of barriers. Because unmet medical and support service needs may result in poorer outcomes for HIV-positive individuals, barriers to these services must be identified and addressed, particularly in rural areas which may be highly underserved.

Introduction

Unmet medical, psychiatric and social service needs are common among people living with HIV/AIDS (Katz et al., 2000; Marx et al., 1997; Piette et al., 1993) and are linked with negative outcomes including poorer adherence to the antiretroviral medication regimens (Catz et al., 2000; Paterson et al., 2000; Spire et al., 2002). Studies of the etiology of unmet needs among HIV-infected individuals found that most problems were externally controlled such as a lack of available services, HIV-related stigma and discrimination, and long travel distances to services (Huba et al., 2001; Marx et al., 2001; Seals et al., 1995). Such barriers are common in rural areas (Heckman et al., 1998; Lishner et al., 1996). Therefore, HIV-
infected individuals in rural areas may be particularly vulnerable to experiencing unmet needs.

Several published studies identified significant gaps in HIV/AIDS service availability in specific metropolitan areas (Bonuck, 2001; Marconi et al., 1994; Nelson et al., 1993); however, few studies have examined service barriers in rural areas, particularly in the Southern US where approximately two-thirds of rural HIV/AIDS cases reside (CDC, 2000; McKinney, 2002). The South faces significant challenges to addressing the HIV/AIDS epidemic because of rising rates of new AIDS cases (while other regions of the US experience declines or stable rates), high levels of STDs, poor health infrastructures and exceptionally high levels of poverty and proportions of people without health insurance (Beltrami et al., 1999; Kaiser Family Foundation, 2002; Southern States AIDS Directors Work Group, 2003). A national study found that HIV-infected individuals in the South were less likely to receive appropriate medical treatment (Shapiro et al., 1999), suggesting that barriers to accessing medical care are likely to be particularly high in this region.

To identify barriers to obtaining medical and social services that influence medication adherence for people with HIV/AIDS and to understand the impact of rural location on service barriers, we analyzed data from a survey of North Carolina HIV/AIDS case managers. We chose to survey HIV/AIDS case managers because their role of linking patients to services places them in a key position to evaluate the availability of services in their geographic region of practice.

Methods

Sample

The data for this study were obtained as part of a larger study of the adherence practices of North Carolina HIV/AIDS case managers (Reif et al., 2003). A survey, cover letter and $5.00 cash were sent in February 2000 to all 119 HIV/AIDS case managers identified to be employed by state-certified HIV/AIDS case management agencies. Eight case managers were ineligible because they left their position before the survey was received. Of the 111 eligible surveys, 94 were returned for a response rate of 85%. No significant differences were found in rural or urban practice location between respondents ($n=94$) and non-respondents ($n=17$). Study procedures were approved by the university's Committee on the Protection of the Rights of Human Subjects.

Survey

The self-administered HIV/AIDS case manager questionnaire included items about case manager characteristics, client characteristics and service barriers that may influence medication adherence. The questions regarding medical and social service barriers were adapted from the Barriers to Care Scale developed by Heckman and colleagues (1998). We also created an item regarding the availability of substance abuse treatment because relatively high levels of substance abuse have been identified in HIV-positive populations (Galvan et al., 2003). The adapted Barriers to Care Scale contained seven questions, one regarding each of the following: (1) HIV-related stigma, (2) inadequate housing, (3) long travel distances to care, (4) lack of adequate transportation, (5) lack of HIV-trained health professionals, (6) lack of mental health professionals, and (7) unavailability of substance abuse treatment. For each of the seven barriers, case managers were asked to ‘indicate the extent you think each of the following is a barrier to medication adherence in the county.
where the majority of your HIV/AIDS clients live’. Because some case managers practice in more than one county, we specified that they answer the questions about the county where the majority of their clients reside. Responses to the seven barrier questions were on a four-point Likert-type scale ranging from ‘not a problem at all’ to ‘major problem’.

**Statistical analysis**

Using Pearson’s chi-square tests, we explored the relationship between practicing in a rural area and a dichotomized variable indicating whether the case manager considered each of the seven barriers to care a ‘major problem’ or not. We used the Office of Management and Budget (OMB) definition of Metropolitan Area (MA) to determine whether the case managers’ primary county of practice was in a MA or in a non-MA (rural area) (NIST, 1995; Ricketts et al., 1998). Of the 100 North Carolina counties, 48 were reported to be the county of primary practice for at least one case manager. Twenty-nine (60%) of the 48 counties were considered to be outside of an MA. This is comparable to the overall proportion of North Carolina counties (65%) that are not in an MA. We also conducted bivariate analysis, using negative binomial techniques (Jones, 2000), to examine the relationships of case manager characteristics with the total number of the seven service barriers they considered to be a ‘major problem’.

We used multivariate negative binomial regression to examine the relationship between being a rural or urban-based case manager and the total number of the seven barriers that case managers considered a ‘major problem’. The final multivariate model was based on an *a priori* model of possible predictors of service barriers, incorporating variables related to these barriers in the bivariate analyses (*p < 0.20*). The model included a variable for the number of counties in the case managers’ practice area to control for any association between practicing in multiple counties and perceived service barriers. Finally, to control for the potential of biased standard errors because some case managers (*n* = 43) reported on the same county as at least one other case manager, we adjusted for this clustering effect by using the Stata cluster command to obtain robust standard errors (Stata, 1999).

**Results**

**Case manager characteristics**

The North Carolina HIV/AIDS case manager survey respondents were predominately female (86%), 36% were African American and 2% Hispanic (Table I). Forty-one percent reported a primary county of practice that was not in an MA. Just under half, 48%, provided case management services for more than one county (mean = 2; range = 1–11).

**County barriers to medical and social services**

Over half of the case managers (57%) considered HIV-related stigma to be a major problem that influences medication adherence in their primary county of practice (Table II). A majority of case managers also considered lack of adequate housing to be a ‘major problem’ (69%). Lack of psychiatric services was considered to be a barrier for many clients, as nearly two-thirds considered a shortage of mental health professionals willing to treat HIV-infected individuals to be at least ‘somewhat of a problem’ and 57% considered a lack of substance abuse facilities for people with HIV/AIDS to be at least ‘somewhat of a problem’.
For five of the seven barriers, rural-based case managers were more likely to identify the barrier as a ‘major problem’ to medication adherence in their county of practice compared to urban-based case managers (Table III). For instance, 51% of case managers in rural counties reported that finding substance abuse treatment facilities for their clients was a ‘major problem’ compared to 22% of case managers in urban areas ($p < 0.03$). For shortage of mental health counselors and lack of adequate housing, a slightly higher percentage of rural case managers rated these barriers to be a ‘major problem’; however, these differences were not statistically significant.
Bivariate and multivariate analyses of the case manager characteristics associated with a greater number of barriers to care

Case managers practicing in rural areas reported a significantly higher number of county barriers to medication adherence that were a ‘major problem’ than case managers practicing in urban areas ($p < .001$) (Table I). The average number of barriers that were considered to be a ‘major problem’ by rural case managers was 4.1 compared to 2.1 for urban case managers (overall mean = 2.9; SD = 2.0). Case managers with a higher percentage of female clients also reported greater barriers to care ($p = 0.029$).

Multivariate negative binomial regression analysis revealed that case managers from rural areas reported a significantly greater number of barriers to be a ‘major problem’ that influences medication adherence for their HIV/AIDS clients ($p < .001$) (Table IV). Having a higher percentage of female clients was also associated with reporting a greater number of barriers ($p = 0.025$).

Discussion

These study results indicate that North Carolina HIV/AIDS case managers perceive significant barriers to care that influence medication adherence for their HIV-positive clients. For each of the seven potential barriers, a majority of case managers indicated that it was at least ‘somewhat of a problem’ in their primary area of practice. Rural-based case managers reported a significantly higher number of barriers to be a ‘major problem’ than urban case managers did.

For five of the seven specific barriers to adherence, rural-based case managers were significantly more likely to indicate a ‘major problem’. For example, 58% of rural-based case managers indicated lack of transportation services to be a ‘major problem’, while 30% indicated this to be a ‘major problem’ in urban areas. This finding is consistent with studies demonstrating that transportation services are sparser and more difficult to coordinate in rural areas (Heckman et al., 1998; McKinney, 2002). In addition, most rural-based case managers (92%) indicated that HIV-related stigma is a barrier to adherence in comparison to 35% of urban-based case managers. Although not a direct barrier to care, community stigma can result in poorer adherence when it interferes with access to services or when fears of disclosure result in non-adherence to medical recommendations. In a study of HIV-
infected individuals taking antiretroviral therapy, participants reported that because they lived in small, rural communities, they skipped doses when in public to avoid the stigma associated with the possibility that medication-taking could disclose their HIV status (Golin et al., 2002). Other barriers such as inadequate housing and untreated substance use problems may also indirectly influence medication adherence by interfering with an individual’s ability to focus on adhering to medical recommendations.

The findings of this study may be limited by several factors. Although case managers noted a high level of service barriers, this study did not evaluate whether these perceived barriers resulted in unmet needs or poorer medication adherence among HIV-positive individuals; thus, the results must be considered preliminary. In addition, the case managers were asked about barriers that influenced medication adherence; therefore, these results may not be generalizable to overall barriers to care for HIV-infected individuals, regardless of whether they are taking medications. In addition, case managers only answered the service barriers questions for the county where the majority of their clients lived because we expected them to be the most knowledgeable about this county; however, this method resulted in some bias toward the larger rural counties in North Carolina. For instance, of the 48 counties reported to be case managers’ primary practice county, all had populations of 20,000 or more. In contrast, of the 52 North Carolina counties not cited by case

Table III. Rural/urban comparisons of barriers to services reported by HIV/AIDS case managers.

<table>
<thead>
<tr>
<th>Barriers to Services</th>
<th>% of case managers in urban counties that responded that this was a ‘major problem’</th>
<th>% of case managers in rural counties that responded that this was a ‘major problem’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stigma against persons living with HIV/AIDS</td>
<td>0.35**</td>
<td>0.92</td>
</tr>
<tr>
<td>Lack of housing for persons with HIV/AIDS</td>
<td>0.67</td>
<td>0.73</td>
</tr>
<tr>
<td>Long traveling distances to receive health care services</td>
<td>0.17**</td>
<td>0.57</td>
</tr>
<tr>
<td>Lack of accessible transportation for clients</td>
<td>0.30**</td>
<td>0.58</td>
</tr>
<tr>
<td>Lack of health care professionals who are adequately trained and competent in HIV care</td>
<td>0.17**</td>
<td>0.47</td>
</tr>
<tr>
<td>A shortage of mental health professionals who can help address mental health issues</td>
<td>0.28</td>
<td>0.30</td>
</tr>
<tr>
<td>Lack of substance abuse treatment facilities willing to work with HIV clients</td>
<td>0.22**</td>
<td>0.51</td>
</tr>
</tbody>
</table>

$p <0.05; p <0.01$

Table IV. Multivariate negative binomial regression analysis of the predictors of county service barriers.

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Beta coefficient</th>
<th>Standard error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary county of practice is rural</td>
<td>0.65**</td>
<td>0.16</td>
</tr>
<tr>
<td>Number of HIV-positive clients</td>
<td>0.0013</td>
<td>0.0014</td>
</tr>
<tr>
<td>% of clients female</td>
<td>0.0064*</td>
<td>0.0026</td>
</tr>
<tr>
<td>Male case manager</td>
<td>0.071</td>
<td>0.18</td>
</tr>
<tr>
<td>Non-white case manager</td>
<td>0.057</td>
<td>0.12</td>
</tr>
<tr>
<td>High school or associates degree education</td>
<td>0.20</td>
<td>0.13</td>
</tr>
<tr>
<td>Years of case management experience</td>
<td>−0.0015</td>
<td>0.024</td>
</tr>
<tr>
<td>Number of counties in the case manager’s practice area (truncated at 4)</td>
<td>−0.073</td>
<td>0.051</td>
</tr>
</tbody>
</table>

*p <0.05; **p <0.01; †reference category is white; ‡reference category is masters or doctorate degree.
managers as their primary practice county, 18 had populations less than 20,000. More research is needed to identify access barriers in the least populated areas of the state.

Despite the study’s limitations, the findings have implications for the care of HIV-infected individuals. Because unmet medical and support service needs that influence adherence can result in poor medical outcomes, including treatment failure and disease progression (Boden et al., 1999; Nieuwkirk et al., 2001), efforts to identify service gaps and assure that adequate levels of services are available for HIV-infected individuals are called for, particularly in rural areas where the greatest resource deficiencies may exist. Improving access to resources and reducing stigma is especially critical in the South, where HIV/AIDS is growing the fastest and where rural HIV/AIDS cases are the most prevalent. Failure to address gaps in HIV/AIDS service provision in the South may further contribute to the ongoing HIV/AIDS crisis in this region.

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