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HIV COUNSELING, TESTING AND REFERRAL EXPERIENCES OF PERSONS DIAGNOSED WITH HIV WHO HAVE NEVER ENTERED HIV MEDICAL CARE

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The HIV counseling, testing, and referral (CTR) encounter represents an important opportunity to actively facilitate entry into medical care for those who test positive for HIV, but its potential is not always realized. Ways to improve facilitation of linkage to care through the CTR encounter haven’t been explored among HIV-infected persons who have not entered care. We conducted 42 structured and qualitative interviews among HIV-infected persons, diagnosed 5-19 months previously, in Indiana, Philadelphia and Washington State, who had not received HIV medical care. Respondents related individual and system-level barriers, as well as recommendations for improving the effectiveness of CTR as a facilitator of linkage to HIV medical care through more active referrals, and for strengthening the bridge between CTR and linkage to care services. Our findings suggest that standards for active case referral by CTR staff and integration of CTR and linkage to care services are needed.

Counseling, testing, and referral (CTR) services can act as the gateway to medical care and ancillary services for those who test positive for HIV. Current CTR guidelines (Centers for Disease Control and Prevention [CDC], 2001), including the revised guidelines for CTR in health care settings (CDC, 2006), highlight the need for in-person, post-test counseling for those who test positive for HIV. This recommendation for posttest services includes efforts to actively link clients to HIV medical care and other support services as necessary.

Despite current efforts to link infected persons to medical care, a substantial number of HIV-infected persons delay care entry after diagnosis (Fagan, Bertolli, McNaghten, & the NIC Study Team, 2010; Fleming et al., 2000; Samet et al., 1998). Several studies have focused on individual and system-level characteristics to identify factors associated with delayed presentation to care (Reed et al., 2009; Torian, Wiewel, Liu, Sackoff, & Frieden, 2008; Samet, Freedberg, Savetsky, Sullivan & Stein...
2001; Turner et al. 2000). However, there is limited information on the role of the CTR encounter in the initiation of care.

One study focused on the CTR experience from the test providers’ perspective (Myers, Worthington, Haubrich, Ryder & Calzavara, 2003), and two have described characteristics of the testing encounter from the patient’s perspective (Hult, Maurer, & Moskowitz, 2009; Worthington & Myers, 2002). McCoy et al. (2009) described the barriers and facilitators to HIV testing and care for persons with advanced HIV disease currently in care. However, no study, to our knowledge, has investigated how the CTR encounter may influence the decision to enter HIV medical care among those who have not yet entered care.

In this analysis, we used interview data from the Never in Care (NIC) Pilot Project to describe how the CTR encounter influenced the participants’ decision or ability to access HIV medical care among HIV-infected persons who have never received care.

METHODS

STUDY SETTING AND POPULATION

The Never in Care (NIC) Pilot Project is a multisite project designed to enumerate and describe HIV-infected persons who have never accessed care for their HIV infection. The NIC Pilot Project was being conducted in collaboration with 5 health department jurisdictions: Indiana, New Jersey, Washington State, New York City, and Philadelphia. The interview portion of the NIC Pilot Project has a mixed-method design, consisting of both quantitative (structured) and qualitative (open-ended) components. Methods have been fully described previously (Johnson, Bertolli, Reed, & the NIC Project, 2008).

The analysis reported here focused primarily on the qualitative data, with use of structured interview data to describe demographic characteristics of the respondents. Qualitative interviews were conducted in three of the five participating areas: Indiana, Philadelphia, and Washington State. Interviews included in this analysis were conducted between February 2008 and November 2009 with respondents diagnosed between January 2007 and March 2009. Potentially eligible respondents were identified through the electronic HIV/AIDS Reporting System (eHARS) and associated laboratory reporting databases. Once identified, respondents were eligible if they met the following criteria: (a) were at least 18 years old at the time of diagnosis; (b) were at least 90 days post HIV diagnosis on the date of selection; (c) had not yet entered care, as evidenced by having neither CD4 + T lymphocyte count or HIV viral load (VL) level reported to the HIV surveillance system or by self-report; (d) resided in one of the three jurisdictions at the time of interview; and (e) spoke English.

HUMAN SUBJECTS PROTECTION

Informed consent was obtained from all respondents. The NIC Pilot Project design and instruments were approved by the institutional review boards of the CDC and participating state or local health departments.

RECRUITMENT

Following locally established protocols, health department staff contacted persons selected for participation to recruit them for the NIC Pilot Project. Interviews took place in different settings, including the respondents’ home and health depart-
ment offices. Locations were chosen based on respondent preference and assurance of confidentiality. Interviewers completed comprehensive training regarding project-specific protocol and methodology, security and confidentiality of sensitive data, and quantitative and qualitative interview techniques. Interviewers recruited up to 25 eligible respondents per area for the qualitative interview from among those who consented to a structured interview. Respondents received a gift card in the amount of $50 for participation in both the structured and qualitative interview components of this study. Both interviews were conducted during the same meeting.

DATA COLLECTION

Qualitative interviews were administered using a semi-structured interview guide, which was developed based on preliminary data from focus groups (Beer, Fagan, Valverde, & Bertolli, 2009). The interview guide consisted of 21 open-ended questions, divided into three domains: health care utilization history, perception of illness and stigma, and access to information about HIV. The majority of qualitative interviews were recorded using a digital audio recording device and lasted an average of 30 minutes. When digital recording was not possible, owing to device failure or respondent refusal, interviewers took detailed handwritten notes.

Additionally, the structured interview component collected data across eight domains, including demographic data and information on HIV testing.

We focused this analysis on responses from the following semistructured interview question: “After you tested HIV-positive, what help were you offered to get into HIV care?” and the standard probe, “Was there something that the person who gave you the diagnosis could have done differently to help you to get into HIV care at that time?”

Respondent characteristics from the structured interview were included to provide context.

ANALYSIS

A professional transcriptionist transcribed all digital recordings verbatim and interviewers reviewed each transcription for errors or clarification.

The research team developed a codebook with structural and thematic codes using a standardized iterative process (MacQueen, McLellan-Lemal, Bartholow, & Milstein, 1998). This process entailed creating an initial draft codebook which coders used to independently code transcripts. Coders would then discuss challenges in applying these codes, make modifications and continue to code with the revised codebook. Coding differences were resolved as they arose through discussion and reevaluation of the data. Thematic analysis was performed on the transcripts using NVivo 8 (QSR International, Australia).

Bivariate analyses were conducted to investigate whether key demographic variables differed by interview location. Differences in categorical and continuous variables were examined using the chi-square test, and t test, respectively.

RESULTS

A total of 42 respondents were included in this analysis. All respondents completed both the structured and qualitative interviews. Of the 42 respondents, the majority were male (71%) and African American (64%). Nearly half (45%) of the respondents were ≤ 30 years of age and 50% earned $15,000 or less per year. Respondents
differed significantly by age across the three areas ($p < .0001$) but did not differ significantly by race, gender, or income. More than half of the respondents (55%) had been diagnosed with HIV in the past 5-7 months (Table 1). Respondents received their HIV test at a variety of locations, with roughly equal percentages testing in a hospital setting (19%), sexually transmitted disease (STD) clinic (17%) or other medical setting (17%). The majority (67%) of interviews were conducted at Site A (Table 2).

Qualitative analysis revealed satisfaction and dissatisfaction with three main components of the testing encounter: counseling, testing, and referral, in addition to experiences with follow-up services, such as case management, that may bridge the gap between testing and care entry. Respondents also described what could have been done differently during the CTR encounter that might have effectively linked them to care.

### COUNSELING AND TESTING

**Satisfied With Testing and Counseling.** Few respondents who described their perception of counseling and testing expressed satisfaction with their experience. Respondents who tested at a prenatal clinic, drug treatment facility or HIV counseling and testing site were more likely to indicate they were satisfied with the encounter. Although some simply stated that they were satisfied without elaborating, more often, respondents who were satisfied explained that their expectations surrounding testing were met because they were provided with sufficient education or information after receiving their positive HIV test results. Others, however, seemed to base their satisfaction on the level of comfort and support provided by the person conducting the HIV test. One respondent described:

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>21-30</td>
<td>19 (45)</td>
</tr>
<tr>
<td>31-40</td>
<td>8 (19)</td>
</tr>
<tr>
<td>41-50</td>
<td>10 (24)</td>
</tr>
<tr>
<td>50+</td>
<td>5 (12)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>30 (71)</td>
</tr>
<tr>
<td>Female</td>
<td>11 (26)</td>
</tr>
<tr>
<td>Transgender</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Black/African American</td>
<td>28 (67)</td>
</tr>
<tr>
<td>White</td>
<td>9 (21)</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>2 (5)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3 (7)</td>
</tr>
<tr>
<td>Yearly income</td>
<td></td>
</tr>
<tr>
<td>$\leq$ $15,000$</td>
<td>21 (50)</td>
</tr>
<tr>
<td>$15,001 – 30,000$</td>
<td>13 (31)</td>
</tr>
<tr>
<td>$\geq$ $40,000$</td>
<td>4 (10)</td>
</tr>
<tr>
<td>Missing</td>
<td>4 (10)</td>
</tr>
<tr>
<td>Time from Diagnosis to Interview (months)</td>
<td></td>
</tr>
<tr>
<td>5-7</td>
<td>23 (55)</td>
</tr>
<tr>
<td>8-10</td>
<td>10 (24)</td>
</tr>
<tr>
<td>11-13</td>
<td>3 (7)</td>
</tr>
<tr>
<td>14-19</td>
<td>6 (14)</td>
</tr>
</tbody>
</table>

*Three hundred percent of federal poverty (2009) for an individual is $<$30,830.
"When they did the quick test she gave me her card, she talked to me and my mom then... Not knowing if I would have that support group, she made herself a support group until I could get to the [AIDS Service Organization]." – (male, 22)

Dissatisfied with Testing and Counseling. Dissatisfaction with the counseling and testing experience was a salient theme among respondents. Those who expressed dissatisfaction were more likely to have been tested at an STD clinic, inpatient facility, private doctor’s office or infectious disease clinic. Most often, dissatisfaction stemmed from a perceived lack of counseling, insufficient counseling, or poor quality of counseling. As one 21-year-old male respondent described, inadequate counseling forced him to seek outside social support. “I basically I had to counsel myself and thank God that I have friends, and a brother and like family that was there for me,” he said.

For others, the negative experience with the tester or counselor may have created a barrier to seeking further assistance.

“So she had the serious tone but she just made it feel like this is the end of the world, what are you gonna do? So. To me... that turned me off. Personally. And it takes me a while to get over some things. (male, 22)

Another respondent described being treated poorly by the medical staff where he received his HIV test, an experience that influenced his decision not to return to that facility for medical care.

“She didn’t take in consideration about how I was feeling... Like if you in that job, just be caring. Just... be considerate... Now I would never go back to [medical facility] and, to get those treatments. No. Never ever. (male, 48)

Narratives also highlighted how inadequate information or misinformation at the time of testing can affect perceptions of the encounter. For example, two respondents explained that they were told medical care was unnecessary at the time of testing based on the assumption that their infection was in the early stages. When they later
learned that this information was incorrect, they became disappointed with their CTR experience because they believed that they had been given incorrect or incomplete information, limiting their ability to make informed decisions about their care.

REFERRALS

Although direct referrals to medical were limited, the qualitative data revealed that respondents were often provided with a passive or active referral to a case manager to be linked to care. For many, the method of referral had an impact on the perception of the CTR encounter and may have influenced their decision and/or ability to access the services to which they were referred.

Active Referral. We defined an active referral as one in which the tester made an appointment for the respondent or transported or accompanied the respondent to an appointment, including an appointment for co-located services.

Though few respondents described receiving active referrals, those who did described supportive interactions and thorough referrals to medical care or other ancillary services. According to one respondent:

she sat down there and she called a bunch of places to see who would help with medical insurance because she said that’s the most important part . . . is to get insurance . . . And she actually called all the places and found out who helped with everything . . . so she made an appointment with them for the next day after I got out. (male, 29)

Although this type of referral seems to have had a positive influence on the overall perception of the testing encounter, it did not result in care entry. Respondents who received active referrals also faced individual and system-level barriers (described later) that affected their ability to access care.

Passive Referral. We defined a passive referral as one in which the tester only provided written material, such as a brochure or a business card, or verbally told the respondent where he/she could seek follow-up services.

More than half of all respondents described receiving passive referrals. This type of referral was often perceived to be of little or no help. Respondents seemed to feel that the gravity of their diagnosis warranted more active assistance. When asked what help was offered after diagnosis, one 52-year-old female respondent said, “None. Well, no, okay, I have to retract that statement . . . They gave me cards.”

For some, it seems that written materials were of little use without someone to provide guidance on how to interpret or use the information. Respondents describe pushing the materials aside, or ignoring them once they left the testing facility. One respondent explained:

After I tested positive, I was, I got a little envelope, manila folder, with information in it. It was more information of HIV, general information, like, what it is, and stuff like that . . . But where that is right now, is, I have no clue. (male, 22)

Others explained that instead of a referral, they were told they would receive a follow-up call or letter from the testing or medical facility giving instructions on follow-up care. That contact never came.

No Referral. Several respondents reported that they received no referral at all. This had a negative effect on the perception of the CTR experience. These respondents
tested in a variety of locations, including an emergency room, STD clinic, jail and an HIV/infectious disease clinic.

One of these respondents described getting a referral to care from a friend, but in the absence of referrals or assistance, others had difficulty identifying or accessing medical services on their own.

PERCEPTION OF FOLLOW-UP SERVICES

Follow-up services were defined as HIV-related services that were accessed through referrals from the CTR encounter. Because most referrals were to case management (with the intent of facilitating linkage to care), the narratives predominantly refer to experiences with case management services.

Satisfied With Follow-Up Services. Few respondents described feeling satisfied with follow-up services. Although limited details were given, these respondents described receiving help and feeling supported as they tried to accept their HIV diagnosis.

Yeah, the case worker came in there and, you know, told me that, you know, she was tryin’ to support me, you know, tellin’ me that it was all right . . . and, you know, there is care and it’s a chronic disease, you know, like, but . . . So I guess he was tryin’ to support me. (female, 28)

Based on these narratives, it appears that most of these services were limited to one time interactions.

Dissatisfied With Follow-Up Services. Most of those who provided information on experiences with HIV-related follow-up services highlighted gaps in or limitations with follow-up services that affected their motivation and/or ability to access medical services. Responses often centered on feelings of disappointed in the case management system. Some described a lack of access to their assigned case manager. As one respondent commented,

Sometimes I guess when I really needed her, the only thing I really kinda hated about it is like I would call and she wasn’t there . . . Then I’d have to talk to somebody else when I really just wanted to talk to her. (female, 23)

Several other respondents described organizational challenges within the case management system, leaving them unable to navigate the complexities of the HIV care system.

I just got lost in the whole shuffle of things . . . I’d call and a lot of times nobody would even answer the phone and I know their opening hours, so I don’t know why they wouldn’t answer the phone. Um . . . they just gave up and I gave up. . . . I would say they gave up first. (male, 40)

BARRIERS TO FOLLOW-UP SERVICES

The barriers described by respondents when attempting to access follow-up services, revealed a gap between referrals provided through CTR and the follow-up services designed to serve as the bridge to care.

Individual-Level Barriers. Several respondents indicated that an individual-level barrier was impeding their progress toward HIV care entry. Multiple barriers were identified, including fear of disclosure, desire for privacy, distrust of medical provid-
ers, lack of motivation, continually entering/exiting jail, having co-morbidities and feelings of shame. Most commonly, however, respondents described needing more time to accept their diagnosis.

Right initially it’s hard to get involved and all that until it starts to sink in and . . . Earlier on you had asked about how if I was in, like, a denial, and I would think maybe at, like, the first month I might have been . . . I don’t even know if denial is the right word, it just, the realization hadn’t hit home yet. (male, 42)

System-Level Barriers. More often than individual-level barriers, respondents described system-level barriers. This included barriers relevant to the HIV care system, criminal justice system, or health insurance system.

Lack of financial means or health insurance was most often listed as the primary reason they hadn’t accessed any HIV-related follow-up services, including case management. The belief that they wouldn’t be able to afford care precluded them from taking any steps toward care entry, including accessing follow-up services.

Others attempted to use follow-up services to alleviate financial barriers to accessing care, but this approach was perceived to be time consuming and difficult. One respondent described his experience attempting to obtain state-funded health insurance.

And she [case manager] said that I needed a Medicare form to get a denial because usually they deny you. She said if they don’t deny you it’s great, but if they do . . . she needs that form so that she can sign me up for another health insurance maybe. But she said that one’s on the waiting list. So. She it’d probably be about another eight months before I even got medical insurance or . . . in to see my doctor, or a doctor. (male, 29)

WHAT COULD HAVE BEEN DONE DIFFERENTLY?

Half of all respondents described what they thought could have been done differently at the CTR session that might have facilitated their timely entry to care. Themes highlighted during the discussion of dissatisfaction with counseling and testing were repeated here.

Most commonly, respondents focused on the counseling component of the CTR encounter, explaining that they needed more counseling at the time of their diagnosis. As one 54-year-old female respondent said, “They could’ve sat down and really talked to me about it.

Several explained that they would have benefited from a more active referral process, and wanted more than a passive referral or no referral at all.

There is just not enough people willing to help people . . . Be more compassionate, offer information . . . to a person. If a person don’t know? Offer it to ’em . . . I mean, if a person don’t [know] the right questions to ask, why should you act oblivious to it and not help . . . ? (male, 48)

Someone do somethin’ differently rather than kinda just pass out pamphlets to you (female, 23)

For others, system-level barriers, described earlier, were the sole barrier impeding their progress toward care entry. These respondents weren’t able to identify anything that could have been done differently that might have helped them enter care.

Still, some said that there was nothing that could have been done differently. Despite satisfaction or dissatisfaction with CTR or follow-up services, these individ-
uals expressed the belief that getting into HIV medical care was their responsibility. One respondent stated:

I’m m — I’m my own worst enemy. She did everything in her power to help me. I did this. You know. I made the mistake of not following up. (male, 28)

DISCUSSION

CTR services are critical, not only for the identification of HIV infection, but also for bridging the gap between diagnosis and care entry for those who test positive for HIV. In this study, respondents who have never received care described their experiences with CTR and follow-up services, providing a window into their perceptions of the CTR encounter, the existing systems for linkage to care, and the influence of these on their decision to access care.

Overall, most respondents described feeling dissatisfied with their CTR experience, predominantly owing to a perceived lack of adequate counseling or information at the time of diagnosis. These data add to previous findings by Rudy et al. (2005), which identified deficiencies within the counseling process. Increased training of CTR staff to provide more thorough posttest counseling in all HIV test settings may be needed to counteract this barrier to accessing care.

Despite the current CTR recommendation to provide active referrals to care following a positive HIV test result (CDC, 2006), most of the respondents in our study describe receiving passive referrals for linkage to care services. Respondents agreed that passive referrals were of little help and provided minimal, if any, assistance in accessing care. As shown in previous studies, active referrals are more successful for linking newly diagnosed persons to care (Craw et al., 2008, Gardner et al., 2005). The addition of a detailed, standard definition of an active referral in future CTR guidelines may be necessary to support the provision of an optimal level of service when referring to or providing linkage to care services.

When attempting to access follow-up services to which they were referred at the time of diagnosis, respondents described system-level barriers, identifying inadequacies in the HIV care system. Frequently, lack of health insurance and lack of access to case management services prevented respondents from moving forward into medical care. Although most respondents live at or below 300% of the federal poverty level (U.S. Department of Health and Human Services, 2009; see Table 1), a common financial threshold for federally funded HIV medical care (National Alliance of State and Territorial AIDS Directors, 2010), many seemed unaware of programs that could assist them. Without ongoing access to case management services to assist them with financial and other systemic barriers, respondents got lost in the complexities of the HIV care system. Respondents in our study appear to have had one or fewer encounters with a case manager, which may not be optimal. Previous studies had shown that for newly diagnosed HIV-infected persons, linkage to care activities are more successful when persons have an average of two or more encounters with a case manager (Craw et al., 2008; Gardner et al., 2005). These data support previous findings describing the benefit of ongoing linkage to care activities that may include multiple follow-up encounters to increase the chances of successful linkage to care.

This study had several limitations. Although interviews were conducted in three project areas, one project area contributed more interviews than the others because this area had higher rates of successful contact with persons selected for participa-
tion. Respondents’ age differed significantly across project areas, but respondents did not differ significantly across areas with regard to other demographic factors such as race, gender, and income. In addition, themes identified were consistent across the three areas. The findings illustrate the experiences and perceived needs of HIV-infected persons who have not yet entered care. However, these may not be representative of all HIV-infected persons who have not entered HIV care in the United States.

The CTR encounter may be the only chance to link certain HIV-infected persons to care, and for this study group, the process failed. In 2006 the CDC revised CTR guidelines to recommend opt-out testing in all health care settings (CDC, 2006). With increased adoption of these recommendations, we anticipate an increase in the number of HIV infections identified (Millen, Arbalaez, & Walensky, 2008; Saag, 2007). However, to ensure the full public health benefit of increased diagnosis, all who are diagnosed with HIV must be linked to HIV medical care.

Timely linkage to care is believed to be a key factor in decreasing transmission but may be an increasing challenge as expanded testing leads to increasing diagnoses, particularly during a time when budget cuts continue to reduce funding for HIV-related services. Although an HIV diagnosis alone has been shown to reduce transmission risk behaviors (Pinkerton, Holtgrave, & Galletly, 2008), those who have not entered care do not have the benefit of ongoing prevention education or antiretroviral therapy, which may further reduce transmission (Granich, Gilks, Dye, DeCock & Williams, 2009, Lima et al., 2008). Taken together, these considerations highlight the need to strengthen CTR and linkage to care services.

Whereas it is important for health jurisdictions to have the ability to tailor CTR and linkage to care services to meet the unique needs of their communities, our findings suggest that more thorough counseling at the time of diagnosis, clear standards for active referral to care by CTR staff and more seamless integration of CTR and linkage to care services are needed.

REFERENCES


HIV COUNSELING, TESTING, AND REFERRAL EXPERIENCES


