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# OVERCOMING CHALLENGES TO HIV MEDICAL CARE-SEEKING AND TREATMENT AMONG DATA TO CARE (D2C) PROGRAM CLIENTS IN BATON ROUGE AND NEW ORLEANS, LOUISIANA

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## Abstract

Data-to-Care (D2C) uses U.S. public health surveillance data to identify persons with diagnosed HIV who are not receiving adequate medical care. These persons are linked to care and ancillary social services through personalized outreach. We conducted semi-structured interviews with 36 adults with HIV in Louisiana who were engaged for the first time or re-engaged back into HIV care through D2C efforts. Before D2C program staff contact, nearly 40% were not contemplating HIV care. Program clients cited barriers to HIV care including difficulties with appointment scheduling and transportation, healthcare service and drug costs, low motivation, and competing non-HIV health needs. Thirty-four of the 36 clients said D2C staff helped them overcome these barriers. Clients also described psychosocial support from D2C staff. After receiving D2C program assistance, over 90% of clients reported consistently receiving HIV medical care and taking medications. Our findings suggest D2C staff successfully identified client needs and provided tailored assistance.

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**Keywords**

Barriers to HIV care; Data-to-Care (D2C); medical care engagement

Diagnosing persons with HIV (PWH) and linking them to treatment with antiretroviral therapy (ART) is essential for viral suppression, preventing new infections, and meeting national HIV prevention and care goals (Cohen et al., 2013; Eaton et al., 2014; Fauci et al., 2019; Sharma et al., 2019). Of all PWH in the United States (U.S.) from 2018-19, 81% were prescribed ART, 78% were retained in care, and 62% achieved viral suppression (<200 copies/mL) in the previous 12 months (Centers for Disease Control and Prevention, 2020).

*Data-to-Care* (D2C) is a public health strategy that uses U.S. state laboratory surveillance data to identify PWH who do not appear to be in HIV medical care and link them to health and social services (Beltrami et al., 2018; Sweeney et al., 2019; Sweeney et al., 2013). Many state health departments use D2C (Bove et al., 2015; Buchacz et al., 2015; Hart-Malloy et al., 2018; Herwehe et al., 2012; Saafir-Callaway et al., 2020; Tesoriero et al., 2017; Udeagu et al., 2013). D2C implementation details often vary between jurisdictions to meet local needs. In general, after identifying potentially out of care clients, staff from health departments or non-health department care facilities attempt to contact the clients, confirm that they are out of care and still reside in the jurisdiction, and offer help to link or re-link them to appropriate health and social services.

Collectively, D2C studies often assess the number of PWH contacted, linked, or re-linked to medical care, or program staff and client acceptability (Buchbinder et al., 2020; Dombrowski et al., 2016; Evans et al., 2015). For example, in their D2C study in Louisiana, Anderson et al. reported that PWH who had fallen from care were 17% more likely to return to care, and PWH with new HIV diagnoses who were not yet receiving care were 56% more likely to link with care if they received D2C services when compared with persons who did not receive D2C interventions (Anderson et al., 2020).

Beyond enumerating client linkage or re-linkage to care rates or general willingness to accept D2C services, surprisingly few studies examine how clients themselves perceive their barriers to HIV medical care or how they think D2C programs can best assist them. To remedy this, Anderson et al. called for new exploratory and qualitative research to better understand which PWH are helped by D2C programs and why (Anderson et al., 2020). Our paper helps fill this gap. We describe D2C client perspectives obtained from in-depth qualitative interviews with PWH who were engaged or re-engaged in medical care through state funded D2C programs in Baton Rouge and New Orleans, Louisiana. These cities are ideal locations for conducting our research because they are part of the state's exemplary and long-established D2C program, called "LA Links" (Anderson et al., 2020; Sweeney et al., 2018). Learning directly from D2C clients augments and complements comparable data collected from D2C staff, which in the case of Baton Rouge and New Orleans, we describe elsewhere (Roland et al., 2022).

We had three study objectives: (1) identify clients' reasons for why they were not in care prior to D2C contact; (2) learn clients' opinions on how D2C staff helped address their needs; and (3) describe how clients' HIV-related care and treatment behaviors changed from before to after they received D2C services. Our findings described below indicate that the D2C program successfully provided tailored assistance to help clients overcome barriers to care, and also motivated clients to seek and obtain HIV medical care. After receipt of D2C services, we show that nearly all the clients in our study moved from getting little or no care to receiving HIV care. Moreover, they intended to remain in care in the future.

PWH clients in other jurisdictions likely vary both in terms of the barriers they face, as well as in their level of personal readiness and ability to seek and obtain medical services. Our study shows that by learning directly from clients about their barriers and motivational impediments to HIV medical care, D2C program staff elsewhere can become better prepared to provide tailored and effective assistance.

## Methods

We conducted our study in Baton Rouge and New Orleans. We used a cross-sectional qualitative research design. The Louisiana Department of Health (LDH) began LA Links in 2013, a D2C program to assist out-of-care PWH clients, including many who reside in these two cities (Anderson et al., 2020; Sweeney et al., 2018). This program provides outreach, linkage case management, and patient navigation services (Sweeney et al., 2018). Compared with other urban areas, in 2018 Baton Rouge and New Orleans ranked fourth and sixth in diagnosis of new HIV infections, respectively (Louisiana Department of Health, 2019). We selected these two cities because of their high numbers of PWH and established D2C programs. Baton Rouge and New Orleans D2C services are offered when surveillance shows PWH have no evidence of HIV laboratory results. These persons never started or dropped out of medical care and need to be re-engaged. Other PWH may have high viral load test results, suggesting they are in care but experiencing treatment failure (e.g., difficulty obtaining or consistently taking ART). LA Links assigns PWH in these varied situations to "linkage to care coordinators" who attempt to contact them, learn more about the nature of their care challenges, and provide tailored assistance.

### Client Recruitment, Eligibility, And Consent

After CDC IRB approval (protocol number 7072), linkage to care coordinators gave recruitment flyers to their clients. Interested clients phoned numbers on our flyer. We screened them for eligibility: men and women aged 18 years or older living with HIV; residing within one of the cities; successfully linked or re-linked to HIV medical care or started or re-started ART through the D2C program; and able to provide consent. Eligible individuals provided written informed consent and were scheduled for in-person interviews. Between 2018-2019, we recruited and interviewed 36 clients.

### Data Collection

Our interview guide included both structured questions to learn clients' sociodemographic characteristics as well as semi-structured open-ended questions about facilitators, barriers, and experiences with HIV medical care and ART. Other questions explored clients' medical care-seeking and medication-taking behaviors before and after they received D2C services.

We also asked clients how D2C staff helped them. Interviews lasted approximately 60 minutes. We transcribed audio-recordings verbatim and redacted identifying information.

## Data Analysis

First, we computed percentages for client sociodemographic characteristics based on their structured question responses. Next, we uploaded the interview transcripts into an NVivo® (version 12) software database, and used content analysis methods for coding and analysis (Carey & Gelaude, 2008; Kripendorff, 2013; Leech & Onwuegbuzie, 2007). We created descriptive codes to correspond to different types of clients' beliefs, attitudes, opinions, experiences, and behaviors present in the transcripts (MacQueen et al., 1998). Using NVivo®, we assigned the codes to specific text passages that contained the beliefs, attitudes, opinions, experiences, and behaviors. To ensure reliability and decrease potential coding errors, we compared how coders in our study team used the codes and employed Cohen's kappa to measure strength of agreement (Hruschka et al., 2004; Landis & Koch, 1977). Cohen's kappa is a better measure of inter-coder reliability in qualitative data coding compared with simple percentage agreement because it adjusts for estimated agreement due to chance (Carey et al., 1996; Hruschka et al., 2004). There was substantial agreement: 94% of codes had kappa values greater than 0.7. Coders resolved remaining discrepancies through discussion. We tallied frequencies of assigned codes to identify common patterns.

To assess how clients' HIV-related care and treatment behaviors changed from before to after they received D2C services, we adapted concepts used in Prochaska and colleagues' transtheoretical model of behavior change, alternatively known as the stages of change model (Prochaska & DiClemente, 1983; Prochaska et al., 1992; Prochaska & Velicer, 1997). For example in this model, some persons might not be considering doing a specific health-related behavior; others might be thinking about starting the behavior, while different persons might be performing that behavior in varying degrees of consistency. Individuals often change where they are in this behavioral performance continuum over time.

Therefore for our study needs, we created codes corresponding with clients' HIV medical care-seeking and medication-taking behaviors. This allowed us to subdivide our sample into five different subgroups. We labeled and defined these subgroups as follows: "Precontemplation" (clients not seeking HIV care and not taking medications); "Contemplation" (clients thinking about seeking HIV care and taking medications); "Preparation" (clients actively seeking HIV medical care and medication prescriptions); "Action" (clients inconsistently receiving HIV medical care and taking medications as prescribed); and "Maintenance" (clients consistently receiving HIV medical care and taking medications as prescribed). We used these codes twice. First, using these five codes, we classified clients into subgroups based on transcript sections where they described their HIV medical care-seeking and medication-taking behaviors *before* receiving D2C services. Second, we reclassified them using transcript sections where clients described their HIV medical care-seeking and medication-taking behaviors *after* receiving D2C services. This meant that each person in the sample was assigned into one of the five possible "before D2C" subgroups, and again into one of the five possible "after D2C" subgroups. In our

Results section below, we compare clients in the different subgroups, and also examine pre- to post-D2C changes in their HIV medical care-seeking and medication-taking behaviors.

Our comparative approach allowed us to identify differences and similarities in beliefs, attitudes, opinions, experiences, and behaviors within and between the subgroups, as well as examine changes over time between the pre- to post-D2C assistance time periods. Finally, we searched the transcripts within our NVivo® database to identify illustrative quotes typifying the most common patterns within and between the subgroups during both the pre- and post-D2C periods.

## Results

The majority of sampled clients (61.1%, N = 22) resided in Baton Rouge; 38.9% (N = 14) in New Orleans (Table 1). Over half (55.6%, N = 20) were age 40 years or older. All but one (97.2%, N = 35) were Black or African American. The majority were female (63.9%, N = 23). Over three-quarters (77.8%, N = 28) identified as heterosexual or straight. More than one-third (36%, N=13) had less than a high school education; a strong majority (75%, N=27) never attended college. Most were unemployed (63.9%, N = 23) at the time of the interview. Four clients (11.1%) said they had experienced homelessness at some point during the 12 months prior to the interview. In the following sections, we identify client barriers to HIV care and show how clients' care-seeking behaviors changed over the time they interacted with D2C staff.

### Before D2C Assistance: Precontemplation

Before receiving D2C assistance, a large proportion of clients (38.9%, N = 14) were not engaged in medical care, taking medications, or considering getting HIV medical care, indicating they were in the "precontemplation" subgroup (Table 2). Some clients explained they did not understand there were ways to medically treat HIV before they were contacted by the D2C staff, or they faced major life circumstances (e.g., homelessness) that acted as barriers to care. Others said they had been in a state of denial or did not feel ready to face their HIV diagnosis (see illustrative quotes in Table 3). Another common reason was depression, which led to apathy or fatalism. Other persons in the precontemplation subgroup said they were out of care prior to D2C program assistance because of past negative experiences with medical systems.

### Before D2C Assistance: Contemplation And Preparation

Clients in the "contemplation" subgroup believed they should get HIV care or take ART but had not yet acted, and some clients said they previously were in care but wanted to re-start (13.9%, N = 5, Table 2; illustrative quotes in Table 3). Clients in "preparation" said they started trying to find HIV care on their own before first contact with D2C staff (13.9%, N = 5).

### Before D2C Assistance: Action

Four clients in the "action" subgroup (11.1%) started but were inconsistently receiving medical care or taking medications prior to receiving D2C assistance (Table 2; illustrative quotes in Table 3). One client was inconsistent because they were on a fixed income and did not have money to pay clinic fees (illustrative quotes in Table 3). Another described how depression hindered their care. The third client explained they had started care on their own volition around the time D2C staff contacted them. The fourth client mentioned difficulties finding transportation to an inconveniently located provider's office. This same individual did not see value in attending doctor appointments because they successfully took their medications.

### Before D2C Assistance: Maintenance

Four clients in the "maintenance" subgroup (11.1%) reported that prior to contact by D2C program staff, they were receiving medical care and taking ART (Table 2). This could be due to out of date or incomplete surveillance records, or client's self-perceived behaviors not aligning with medical definitions of what it means to be in care and taking ART as prescribed. One client said they had a prior history of not being in care, even though they believed themselves to be in care at the time of initial D2C contact. Another client did not know why their D2C coordinator had contacted them and speculated it might have been related to their elevated viral load.

### After D2C Assistance: Action And Maintenance

Clients described remarkable increases in their HIV care-seeking and treatment behaviors after they received D2C assistance (Table 2). An overwhelming majority (91.7%, N = 33) had moved into the "maintenance" subgroup. These clients reported consistently getting medical care and taking their HIV medications as prescribed after receiving assistance from D2C staff. These clients unequivocally stated they were in care, taking their ART, and wanted to continue in care.

Consistent with other LA Links studies, our findings suggest that D2C staff were successful in helping nearly all clients overcome care and treatment barriers, such as lack of transportation or helping them manage mental health issues like depression (Anderson et al., 2020; Roland et al., 2022). Only three participants (8.3%; in "action" subgroup) reported any inconsistency in receiving medical care or taking medications. One of these three clients did not feel comfortable with their doctor due to a perceived lack of privacy and feeling bullied at the clinic and planned to talk with their D2C care coordinator to find a new doctor. The second client mentioned appointment scheduling difficulties. The third client believed their current doctor took too long and encountered prescription delays, and wanted a new doctor.

### How D2C Helps Address Clients' Individual And Structural Barriers To Care

Clients cited many individual (e.g., mental health) and structural (e.g., homelessness, lack of money and transportation) barriers to engagement in HIV care. Clients also described ways D2C staff helped them address those barriers, often in an enthusiastic and unequivocal manner. Table 4 lists 12 forms of assistance clients reported their D2C care coordinator provided. On average, clients reported receiving two to three (mean 2.47) forms of assistance. Two clients (5.6%) said they did not receive any assistance. Among the other 34 clients, the most common types of assistance included: facilitating transportation to medical appointments (38.9%, N = 14); help making appointments (33.3%, N = 12); help paying healthcare costs (30.6%, N = 11) including assistance with insurance, Medicaid, disability benefits, and/or other HIV and healthcare-related financial assistance; general encouragement and motivation (25.0%, N = 9); and help obtaining healthcare for non-HIV needs (e.g., dental, vision, mental health, or food pantry assistance). Other moderately common forms included help filling out healthcare paperwork (16.7%, N = 6), providing information and general counseling (16.7%, N = 6), reminders about healthcare appointments or taking medicines (16.7%, N = 6), and going with the client to doctor appointments (16.7%, N = 6). Only clients in the "precontemplation" group before receiving D2C assistance mentioned receiving all 12 assistance types. This suggests that clients in "precontemplation" may face the largest number of care and treatment challenges and therefore may need the most help.

We should not underestimate the psycho-emotional value of D2C services. According to LA Links staff, D2C personnel explicitly attempt to promote feelings of general support, hope, and self-efficacy among their clients (Roland et al., 2020). This is corroborated by clients in our sample. For example, after a D2C care coordinator contacted them, one of our clients described their initial reaction as, "Oh, someone cares." Another client told us, "She called me every day and let me know that there's somebody out there that really cared."

## Discussion

To be eligible for D2C services provided through LA Links, the 36 clients sampled in our study had surveillance records indicating they never accessed care, were out of care, needed to be re-engaged in care, or were in care but experiencing treatment failure (including not taking ART as prescribed, or having not attained viral suppression). Before D2C program contact, over a third of our clients were not thinking about their HIV medical care; nearly another third were considering or beginning to seek care; while the remaining believed themselves to be in medical care to varying degrees and were puzzled why a D2C care coordinator contacted them. It is possible that some clients and public health personnel have different definitions about what constitutes receiving HIV care and taking ART. Despite these initial barriers, many interviewees became connected with medical care services and started or restarted taking ART after D2C. Following receipt of D2C assistance, nearly all clients said they were consistently receiving HIV medical care and taking ART, a remarkable improvement. Only three clients indicated they were inconsistently seeing medical care providers and taking ART after D2C assistance.

The women and men in our sample faced significant individual and structural barriers that interfered with medical care and treatment. Many of the challenges faced by PWH like those in our study are created or strongly influenced by community-wide social determinants of health, and require solutions that address significant inequities that too often impact vulnerable populations in the U.S. South and other regions (Jeffries & Henny, 2019). For example, over a third of our participants had not completed high school, the majority were unemployed, and several experienced homelessness in the 12 months before the interview. Moreover, clients understood why they were not in care or taking ART before D2C. Common reasons included: poor understanding of HIV medical care and ART treatment;

denial or difficulty coping with their diagnosis; feelings of depression, apathy, or fatalism; negative prior experiences with health systems (e.g., arduous paperwork requirements) or clinicians who treated them badly; difficulties paying for services or ART; inconveniently located health care facilities and lack of transportation; and challenges in finding a doctor. Depression, denial, fatalism, prior negative experience with the medical system, difficulty finding a doctor, inconvenience, and financial and insurance difficulties often are cited as barriers among PWH (Bauman et al., 2013; Brewer et al., 2018; Dombrowski et al., 2015; Moneyham et al., 2010; Remien et al., 2015; Yehia et al., 2015).

Except for two persons, all other clients in our sample reported their D2C care coordinators provided tailored assistance to address their specific needs and barriers to HIV care and treatment. We believe this tailored approach explains why Baton Rouge and New Orleans D2C programs were successful in helping most clients increase their consistent HIV medical care-seeking and ART-taking behaviors. Based on clients' statements, of the 12 identified forms of assistance that D2C staff provided, the most frequent assistance included: helping clients obtain transportation to health care facilities; medical appointment making, financial assistance for healthcare-related services and ART, general motivation and encouragement, and help with non-HIV health needs. Other D2C studies have described the importance of transportation, health insurance, or different behavioral health needs (Anderson et al., 2020; Sweeney et al., 2018). D2C program staff may provide services comparable to patient navigators, case workers, or others in different client assistance programs (Koenig et al., 2021). While helping individual clients obtain HIV medical care, complementary efforts should be made to improve broad on-going inequities and structural impediments that adversely affect community-wide public health (Jeffries & Henny, 2019; Menza et al., 2021).

In a separate but related component of our work in Baton Rouge and New Orleans, we also interviewed D2C program staff in the same two cities to learn their views of clients' barriers to HIV care (Roland et al., 2022). Barriers mentioned by staff included challenges partially overlapping with those identified by clients and described in our current paper, such as transportation, financial challenges, unstable housing, mental illness, and adverse interactions with some healthcare providers. However, we believe that program staff likely responded based on aggregated experiences across multiple clients. Therefore, talking directly with clients is important to understand individual client experiences, which is needed for providing tailored assistance. Barriers to obtaining care or taking ART for one client are not necessarily the same as those for other clients. Having individual-level client data in our current analysis also allowed us to identify different client subgroups who had varied combinations of barriers to care. These client subgroups were not discernable using data from staff interviews because individual-level client variation was lost. We recommend that future investigators in other jurisdictions interview both D2C clients and staff separately, because findings from each group may yield different insights. Providers likely can describe common cross-cutting and broad community-wide issues, while clients likely can provide greater detail, report less-common barriers to care, and describe their specific needs, experiences, and circumstances. Data from both groups are useful for designing maximally responsive and effective D2C programs.

Our study has limitations. The LA Links program in Baton Rouge and New Orleans may not reflect D2C programs in other regions (Beltrami et al., 2018; Sweeney et al., 2019; Sweeney et al., 2018). Our sample size was modest. By necessity our sample included only PWH who received D2C services; we could not include potentially eligible persons who the program could not locate or those who refused D2C services. This may have introduced sampling bias. We had no access to clients' medical care records and could not corroborate self-reported care-seeking and ART use behaviors. Some clients likely had recall difficulties or perhaps gave us "socially desirable" responses. As a cross-sectional study, we could not follow up with clients to see how long they remained in care and continued ART long after our interviews. We also do not know how D2C program functionality or client experiences may have changed during the recent COVID-19 pandemic.

However, our findings are valuable due to our focus on client views on their barriers to care, which we believe complement and augment data obtained only from D2C staff or examination of medical care and surveillance records. Understanding challenges and types of tailored assistance provided by the D2C programs in Louisiana can provide useful ideas to program planners in other jurisdictions. Another contribution is that we show how clients think the D2C programs assist them. This also can help program planners anticipate the types of assistance their staff may need to provide.

Not all out-of-care PWH are equally interested in or be able to enter or re-enter HIV medical care. To provide effective D2C services, it is important that D2C staff first learn a client's specific needs and then provide tailored services. Our use of the stages of change model shows that there was variation among clients when they are first contacted by their D2C program. To our knowledge, no prior studies have used the stages of change model to assess D2C client progression to care. Future studies could explore alternative or better ways to identify client subgroups. D2C programs often will need to provide personalized forms of assistance based on client readiness to engage. To varying extent, D2C staff may also need to strengthen clients' motivation to seek and remain in HIV medical care. Nurses and other healthcare workers can play major roles in encouraging and motivating PWH who have diverse needs (Centers for Disease Control and Prevention, 2019; Holstad et al., 2006).

D2C programs are interventions explicitly designed to provide support services to PWH. Social support is associated with successful care re-engagement and HIV outcomes (Burgoyne, 2005; Cabral et al., 2018; Chang et al., 2019; Nokes et al., 2012; Power et al., 2003). D2C programs like those in Baton Rouge and New Orleans may help PWH cope with hopelessness or demotivating negative emotions and build stronger self-efficacy simply by showing clients care and compassion. Moreover, Baton Rouge and New Orleans D2C staff provided important instrumental support (e.g., transportation, information, help with paperwork, resolution of financial problems) that our clients clearly needed and explicitly valued. Social support can affect mental and physical health by providing psycho-emotional benefits (Caplan, 1974; Cassel, 1976; Cobb, 1976), as well as instrumental or physical forms of assistance (e.g., labor, material resources, information for solving problems) (Cohen, 1985). There is a long history of service providers offering interventions to deliver social support services to promote health (Gottlieb, 1988). Effective D2C programs not only rely on accuracy of HIV surveillance data, but also need dedicated and knowledgeable staff who build trust with and provide multiple forms of help to their clients (Sweeney et al., 2019).

## Conclusion

All U.S. state health department HIV control programs receive federal funds from CDC to implement, expand, and support D2C (McCree et al., 2019). Insights from established D2C programs are valuable for helping less established programs (Sweeney et al., 2019). It is important to develop and evaluate improved and sustainable interventions that help PWH stay in care and treatment after D2C program assistance ends. For example, if transportation was a barrier to an individual going to their doctor, there is a danger that they will fall out of care after a local D2C program stops providing transportation assistance. Second, there is a need to identify best ways to train D2C program staff on efficiently and effectively identifying client care and treatment barriers, as well as delivering tailored and useful forms of help. Lastly, future studies should identify administrative structures that best allow D2C program staff to develop and implement effective and personalized relationships based on trust and respect with their clients.

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### Key Considerations

- Many persons with HIV (PWH) are not linked with care or receive antiretroviral therapy (ART) immediately after diagnosis. Once linked, others may fall out of care or not consistently take ART as prescribed.
- PWH who are not in care often face multiple barriers. Examples include structural and economic challenges such as stigma, homelessness, poverty, lack of transportation, or competing demands on their time. Other factors that may hinder HIV care include mental health issues like depression, non-HIV healthcare needs, and low personal knowledge, motivation or self-confidence needed to seek HIV medical care.
- "Data to Care" (D2C) is a public health strategy that uses surveillance data to identify PWH who do not appear to be in care, and provides them with help to start or re-start care.
- Nurses, social workers, health educators, or other personnel who provide D2C linkage to care services should identify the specific set of needs that hinder clients from receiving adequate HIV medical care. Not all out-of-care PWH clients or groups have the same needs.
- After identifying a client's specific needs, D2C personnel should provide tailored services conveyed in a compassionate, respectful, supportive, and sustainable a manner as possible.

## Table 1.

Sociodemographic characteristics for Data to Care (D2C) clients in Baton Rouge and New Orleans, Louisiana, 2018-2019 (Sample N = 36)

| Characteristic | Percent (number) |
|---|---|
| City of Residence | |
| Baton Rouge | 61.1 (22) |
| New Orleans | 38.9 (14) |
| Age in years | |
| 20-29 | 13.9 (5) |
| 30-39 | 30.6 (11) |
| 40-49 | 13.9 (5) |
| 50+ | 41.7 (15) |
| Race | |
| Black/African American | 97.2 (35) |
| White | 2.8 (1) |
| Sex at birth | |
| Female | 63.9 (23) |
| Male | 36.1 (13) |
| Sexual orientation | |
| Gay | 13.9 (5) |
| Straight | 77.8 (28) |
| Bisexual | 5.6 (2) |
| Other | 2.8 (1) |
| Level of education (highest level attained) | |
| < High school diploma | 36.1 (13) |
| High school diploma or GED | 38.9 (14) |
| Some college | 16.7 (6) |
| College graduate | 5.6 (2) |
| Graduate school | 2.8 (1) |
| Employment Status | |
| Full time | 19.4 (7) |
| Part time | 16.7 (6) |
| Unemployed | 63.9 (23) |
| Homeless any time in the past 12 months | |
| Yes | 11.1 (4) |
| No | 88.9 (32) |

## Table 2.

HIV care-seeking client behavior according to their readiness for receiving HIV medical care before versus after receipt of Data to Care (D2C) program assistance, Baton Rouge and New Orleans, Louisiana, 2018-2019 (Sample N = 36)

| **Readiness to receive HIV care subsample**[*1] | **Before D2C assistance Percent (number)**[2] | **After D2C assistance Percent (number)** |
|---|---|---|
| Precontemplation (not seeking HIV care, not taking medications) | 38.9 (14) | 0 |
| Contemplation (thinks they should seek HIV care and take medications) | 13.9 (5) | 0 |
| Preparation (actively seeking HIV medical care and medication prescriptions) | 13.9 (5) | 0 |
| Action (inconsistently receiving HIV medical care and taking medications as prescribed) | 11.1 (4) | 8.3 (3) |
| Maintenance (consistently receiving HIV medical care and taking medications as prescribed) | 11.1 (4) | 91.7 (33) |

[*] Based on client’s self-reported behavioral descriptions

[1] These subsample labels are partially derived from prior “stages of change” literature in non-HIV research; see Prochaska, J.O. and DiClemente, C.C. (1983) Stages and processes of self-change of smoking, toward an integrative model of change. Journal of Consulting and Clinical Psychology, 51, 390-395. doi:10.1037/0022-006X.51.3.390; Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change: Applications to addictive behaviors. American Psychologist, 47(9), 1102-1114; and Prochaska, J.O. and Velicer, W.F. (1997) The Transtheoretical Model of Health Behavior Change. American Journal of Health Promotion, 12, 38-48. http://dx.doi.org/10.4278/0890-1171-12.1.38

[2] “Before D2C” data missing for 4 clients.

## Table 3.

Illustrative interview quotes showing barriers to HIV care among clients before receipt of Data to Care (D2C) program assistance, Baton Rouge and New Orleans, Louisiana, 2018-2019 (Sample N = 36)

Interviewer: At the time that you were first contacted [by your D2C linkage to care coordinator], were you trying to get into care? Were you looking for an HIV care provider?

Respondent: No… ‘Cause I couldn’t accept it. *[Client in precontemplation subsample]*

Interviewer: At that time that she contacted you, were you doing anything? Were you trying to get into care?

Respondent: No.

Interviewer: Were you looking for any type of provider?

Respondent: No.

Interviewer: No? You just were not ready–

Respondent: No, I wasn’t ready to deal with it…I was not ready to face the card that I was dealt. And that’s why I was basically runnin’. *[Client in precontemplation sample]*

Interviewer: So at the time that she first contacted you, were you trying to get into care?

Respondent: No. I was just in that dark place.

Interviewer: Were you looking for an HIV care provider?

Respondent: I wasn’t—I almost gave up. You know, I was thinking about it. Cause I’m like, “I’m going to die anyway, so.” *[Client in precontemplation subsample]*

Interviewer: Were you looking for a provider?

Respondent: Nope.

Interviewer: Okay. Why not?

Respondent: Depressed. Just…Depressed. Didn’t care. I was just goin’ to die. So, yeah, I was depressed. It was sad.

Interviewer: Did you think you needed to be in treatment at the time?

Respondent: Mm-mm. I didn’t.

Interviewer: Why not?

Respondent: I didn’t think I needed my life, at the time, so. Why would I need to be takin’ medicine for? *[Client in precontemplation subsample]*

Respondent: Just the real, the red tape I had to go through, man, it’s just, it’s one thing, one month it’s this way, the next month it’s another way, and seem like now things just straight, and it’s supposed to be how it’s supposed to be, now I don’t know. But I haven’t been through that kind of stuff lately, no more.

Interviewer: Did you think that you needed to be in treatment then?

Respondent: Yeah, I needed to be in treatment. Yes, indeed! Yeah, I needed to be in treatment. And I did…sometime I get down there and try and hit a roadblock, and I say, man, I ain’t gonna keep puttin’ up with this. *[Client in precontemplation subsample]*

Respondent: [Getting into HIV care] had crossed my mind a couple of times, but I wasn’t actively looking because I had all the intentions of going back where I was before, but I had troubles finding them cause I wasn’t sure where they moved to because they used to be on Partridge right down the road and I think they moved them to the bigger buildings over there off of Tulane Canal. And I was never able to find them. *[Client in contemplation subsample]*

Interviewer: So how were you looking for a new provider?

Respondent: Like going Google and HIV care, doctors and stuff like that.

Interviewer: So you were just trying to look for a list of people here you could go to?

Respondent: Yes, ma’am.

Interviewer: Okay, what made that hard to find somebody else to go to?

Respondent: Like, cause they was giving me appointments that was 4 or 5 months. Or I had to go through a process and it’s going to take about a month for me to actually get medication.

Interviewer: So you didn’t feel like anybody could get you in fast enough for you to stay in care?

Respondent: Yes, ma’am. *[Client in preparation subsample]*

Interviewer: So how long had you been trying to find a provider closer to you that you could get to?

Respondent: About a year…Then I got in touch with Miss [D2C care manager]. She got me a primary doctor.

Interviewer: So was transportation the only reason you were having trouble getting a doctor?

Respondent: Yes. *[Client in preparation subsample]*

Respondent: I get in them moods, depression mood, but then I think about it. Well, there’s nothing else I can do about it. *[Client in action subsample]*

Respondent: I was doing what I had to do—take my medication. I stayed on top of [taking my medications]. *[Client in action subsample]*

## Table 4.

Types of assistance provided to clients by their D2C linkage to care coordinator, Baton Rouge and New Orleans, Louisiana, 2018-2019 (Sample N = 36)

| **Type of Assistance** | **Total number of clients reporting assistance type** |
|---|---|
| Providing/arranging transportation to healthcare appointments | 14 |
| Scheduling HIV healthcare appointments | 12 |
| Enrollment in financial support and insurance (includes health insurance, Medicaid, disability, or other healthcare financial assistance) | 11 |
| General encouragement and motivation | 9 |
| Help obtaining dental, food pantry, vision, and/or mental health services | 8 |
| Healthcare paperwork completion | 6 |
| Providing information and general counseling | 6 |
| Providing appointment or ART reminders and check-in communications | 6 |
| Accompany client at medical appointments | 6 |
| Help finding a doctor | 5 |
| Help finding housing | 4 |
| Provide referral to a support group | 2 |
| No assistance provided | 2 |
| Total (excludes "No assistance provided") | 89 |
| Mean number of assistance types provided per client (N = 36) | 2.47 |