An Assessment of A Pilot Peer Navigation Program
Linking HIV Positive Clients of Harm Reduction Services
With Ryan White Clinical Service Providers

TECHNICAL REPORT

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INTRODUCTION

Cicatelli Associates Inc (CAI) recently piloted a peer navigation program aimed at linking HIV positive clients of harm reduction services with Ryan White service providers. This pilot program was part of a Minority AIDS Initiative (MAI) pilot program funded through the Health Resources and Services Administration (HRSA) to provide training and technical assistance to: 1) develop, implement and pilot projects establishing “partnerships” between Harm Reduction Services in three of the highest “unmet need” geographical areas in the United States and Ryan White HIV/AIDS Program Clinical Services and 2) demonstrate effective models for utilizing patient navigation to enroll, retain and re-engage active substance users in HIV treatment and care.

This pilot program was assessed by CAI’s research and evaluation division to help the program identify areas of patient navigation that were effectively employed to navigate drug users into clinical care services. Results of this research endeavor directly inform programmatic planning as well as the field of research which aims to improve healthcare accessibility for current drug users living with HIV/AIDS.

The Program

The MAI/HRSA pilot program conducted at CAI had the following objectives: 1) Train patient navigators at harm reduction sites; 2) Effectively link drug users with HIV/AIDS clinical services; 3) Improve retention and adherence among drug users. The approach aimed to assist Ryan White-funded clinical providers to enroll and retain minority populations living with HIV/AIDS in treatment and care services. Programs were implemented in New Jersey and New Mexico. Patient navigation is a practice that has the potential to significantly impact access to clinical care for HIV/AIDS among drug users.

The Evaluation

CAI’s research and evaluation division conducted an assessment of this pilot program. The assessment was guided by specific research questions, such as what areas of patient navigation were effectively employed with clients of harm reduction services, and did the peer navigation model help retain clients in care and improve their adherence to appointments? To answer these questions, CAI’s research and evaluation division conducted:

1. Key-informant interviews with program clinical staff, and
2. Utilization of secondary programmatic tracking data on peer navigators and patients navigated to examine trends in navigation over time.

Results of this assessment have direct implications for programs aimed at navigating difficult-to-reach clients living with HIV/AIDS into HIV clinical services.
LITERATURE REVIEW

The harm reduction approach has been useful in reducing drug users’ risks of contracting HIV infection and other blood borne illnesses. However, maintaining drug users in HIV/AIDS clinical care services remains challenging. In one study of regular heroin users in Australia, it was found that 35% were not engaging in overdose prevention practices, and common interview themes included indifference toward life, death as an occupational hazard of drug use, and death as a welcome relief. Indeed, low-threshold measures of behavior change, such as entry into HIV clinical services, can represent a comparatively large change in behavior from the perspective of certain drug using populations.

Recent evidence suggest that variable rates of testing, delayed testing and diagnosis, and healthcare accessibility continue to remain a problem among drug using populations. In a recent study of people who use injection drugs (PWUID) across 33 US states, it was estimated that 42% of PWUID were diagnosed with HIV infection at a late stage of disease progression. There is clear need for improved programs and interventions which affect healthcare accessibility, particularly for PWUID, and particularly at a systems level.

Peer navigation is a health services intervention aimed at improving healthcare accessibility and adherence for hard-to-reach populations, or potential clients of healthcare services, by providing the client with navigation through the complexities of healthcare for HIV/AIDS. The program conducted by Cicatelli Associates Inc. aimed to train Harm Reduction and clinical staff in the peer navigation model in order to improve access to care for drug users currently attending harm reduction services.

Much of the current research on harm reduction interventions surrounding PWUID aims at enrolling PWUID into harm reduction programs and reducing HIV transmission risk. While this approach targets a low-threshold of behavior change for PWUID in line with the harm reduction model, it can be taken one step further to address accessibility to healthcare services for HIV-infected PWUID. In one qualitative analysis of drug users in New York City, getting needed programs and services as well as handling health problems were identified as desired outcome areas of harm reduction programming. Beyond access to material resources, there are factors such as access to HIV testing, trouble making appointments, lack of sufficient follow-up, and stigma which impact HIV-positive PWUID accessibility to clinical services.

Further, drug users may have a pre-existing aversion to the healthcare system which may in part be attributed to the experience of discrimination by healthcare providers. Drug-related stigma has been associated with damaging behavioral sequelae such as poor mental health, secrecy as a method of coping, riskier sex mitigated use of safer injecting services, and poor relationship maintenance. Further, it is possible that intra-group drug-related stigma and layered HIV/Drug-related stigma may be operational within drug users. By implementing a navigation program which utilizes navigators for PWUID into healthcare services for HIV-infection, it is likely that these factors which typically bar accessibility will increase program participants’ access to clinical services.

EVALUATION QUESTIONS
The aim of this evaluation is to assess the pilot peer navigation program. Findings from this endeavor will have implications for peer navigation programs linking clients of harm reduction services with HIV clinical care services.

Specific research questions that CAI’s research and evaluation division asked included:

1. What were navigators’ experiences in implementing the intervention?
2. Which components of the navigation intervention were effective for improving clients’ recruitment, retention and adherence?
3. Do specific navigator activities and responsibilities correspond to specific instances of patient navigation?

These questions were answered by conducting key-informant interviews with participating harm reduction services and clinical staff, and by conducting secondary data analysis of programmatic tracking data.

METHODS

To conduct an evaluation of the pilot program, we employed a mixed quantitative and qualitative analytic strategy. The qualitative portion of this research involved conducting semi-structured interviews with staff at harm reduction sites (peer navigators) as well as staff at Ryan White clinical services. The quantitative portion of this assessment included secondary data analysis of programmatic tracking data, particularly with regard to the duties performed by the peer navigator on a weekly basis from time of implementation.

Key-informant semi-structured interviews

Key-informant semi-structured interviews were conducted with 4 peer navigators, 3 Ryan White clinical service providers, and 1 front office staff person. Interviews were conducted over the course of several months, and sometimes involved multiple interview timepoints. Individuals were first asked to provide verbal consent after having been read aloud a consent statement. Each interview was recorded using an Olympus Linear PCM Recorder, and was subsequently transcribed. All audio files were destroyed following transcription. The key informant interviews portion of this assessment involved the collection of primary data, and the research protocol received ethics approval from the Western IRB (WIRB). To protect the identity of persons involved in the program, text alterations were made to quotes which could indicate an individual’s identity. Quantitative data were based upon archived secondary programmatic data and thus did not require IRB review.

Navigation Tracking

As part of the CAI patient navigation program, navigators reported weekly on their activities, including the number of times navigation was provided, as well as other navigator-specific job duties (e.g. communicating with Ryan White services point of contact, number of times navigation was provided into harm reduction services, number of community contacts, number of telephone calls made for navigation, number of unduplicated clients served, and number of
clients for whom education was provided). Navigator tracking forms were used by the CAI program to ensure that navigators were actively completing their duties as navigators.

In addition to tracking navigator activities, both navigators and Ryan White staff were encouraged to keep tracking forms as a mechanism by which to discuss clients’ appointments and needs.

For the purposes of the evaluation, we examined the counts of navigator activities in relation to dates on which patient navigation occurred. Thus, we constructed a secondary analytic database in listwise format where week since baseline for a given navigator was the unit of analysis, with temporal units clustered within navigators. Weekly activity counts were examined in relation to dates on which navigation occurred. The variable representing whether navigation occurred was coded binomially (0,1) to represent weeks in which navigation occurred (0=time period in which navigation did not occur, 1=time period in which navigation did occur). Data were cross validated by examining both navigator and Ryan White services patient tracking forms. Tracking forms were submitted to the CAI program in de-identified format, such that the patient’s identity could never be identified and was thus blinded to the program and study team.

Data analysis

Qualitative data was analyzed using ATLAS software. We developed a grounded theoretical framework for data analysis. We first reviewed all transcribed interviews and created a set of open codes. Following the development of open codes, axial codes were then developed based on emergent themes in the data. Finally, axial codes were combined to formulate theoretical codes detailed in the results section of this manuscript.

Quantitative data was analyzed using STATA 10 analytic software. Means and standard errors were examined for tracking peer navigator program activities. Two tailed T-tests were used to examine mean differences between groups. In order to model binomial outcomes adjusted for inter-navigator variability and time, we used a fixed effects model to generate adjusted odds ratios.

RESULTS

Quantitative findings

In total, navigators identified and navigated 20 patients into Ryan White clinical services (12 in Newark, 2 in Albuquerque, 5 in Camden). Among patients navigated, 53% were male and 47% were female; 75% were 25-44 years old and 25% were 45-64 years old; 15% identified as being of Hispanic or Latino origin; 0% identified their ethnicity as American Indian or Alaskan Native, 10% as Asian, 70% as Black or African American, 5% as White/Caucasian, 0% as Native Hawaiian or Other Pacific Islander, and 15% as Hispanic/Puerto Rican.

Data were collected on 4 patient navigator activities for patient navigators located across three sites (Albuquerque n=2; Newark n=1; Camden n=1). Specific patient navigator activities by week of service are thoroughly illustrated in Appendix A.
Across navigators and sites, the peer navigation program resulted in a cumulative total of:

- 42 novel navigation engagement attempts by navigators;
- 26 new clients for whom at least one navigation attempt was made;
- 172 instances of navigator communication with the Ryan White services point-contact;
- 177 instances of navigation provided into Harm Reduction services;
- 3,085 instances of community contacts;
- 290 navigation related telephone calls;
- 573 new client orientations conducted; and
- 212 clients for whom education was provided.

Navigator-specific activities varied appreciably in relation to specific instances where patient navigation was provided. Table 1 illustrates simple mean differences in instances of navigator activities relative to instances where peer navigation was provided.

| Peer Navigator Activity                              | Instances of navigation during a time period | $|T| | P value |
|-------------------------------------------------------|----------------------------------------------|------|---------|
| Number of instances of navigator:                    |                                               |      |         |
| Not navigating                                       | Mean (SD)                                    |      |         |
| Navigating                                           | Mean (SE)                                    |      |         |
| Communicating with Ryan White services point-contact | 0.7 (0.2)                                    | 2.7 (0.4) | 4.8     | <0.001  |
| Provided navigation into harm reduction services     | 0.79 (0.2)                                   | 2.7 (0.5) | 4.5     | <0.001  |
| Making community contacts                            | 28.3 (2.7)                                   | 13.4 (2.6) | 3.3     | 0.0011  |
| Used telephone for navigation-related activities     | 1.3 (0.3)                                    | 4.4 (0.6) | 5.3     | <0.001  |
| Provided patient education                           | 1.1 (0.3)                                    | 2.9 (0.6) | 2.9     | 0.005   |

In order to better adjust for inter-navigator variability and temporal patterns in navigation, we conducted fixed effects models where the intercept was permitted to vary by navigator (Table 2).
Table 2. The odds of navigation given peer navigator activities, fixed effects model with random intercepts for peer navigators, controlled for time

<table>
<thead>
<tr>
<th>Peer Navigator Activity</th>
<th>Instances</th>
<th>P value</th>
<th>Fixed Effects estimate (SE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of instances of navigator:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicating with Ryan White services point-contact</td>
<td>1.3</td>
<td>0.013</td>
<td>0.58 (0.49)</td>
</tr>
<tr>
<td>Provided navigation into harm reduction services</td>
<td>1.4</td>
<td>0.005</td>
<td>1.15 (0.56)</td>
</tr>
<tr>
<td>Making community contacts</td>
<td>0.98</td>
<td>0.301</td>
<td>0.96 (0.57)</td>
</tr>
<tr>
<td>Used telephone for navigation-related activities</td>
<td>1.3</td>
<td>0.001</td>
<td>0.87 (0.51)</td>
</tr>
<tr>
<td>Provided patient education</td>
<td>4.3</td>
<td>&lt;0.001</td>
<td>0.0 (2.1)</td>
</tr>
</tbody>
</table>

Results in Table 2 exhibit that increases in the number of navigator-specific activities were associated with an incremental increase in the odds that a patient was navigated during that period (Table 2). The only counter-directional relationship observed was the observation of decreased odds for number of community contacts, which was also insignificant. We stipulate that while community contacts are an important component of gaining access to patients, this variable is more likely to exhibit a time-lag effect and/or cumulative effect and thus would not exhibit a significantly positive association in the context of panel data. While these models merely exhibit the existence of a relationship between navigator activities and navigation, it can be assumed that the positive relationship is the byproduct of a navigator increasing those particular duties to respond to the demands of navigating a given patient. The results in the table thus suggest that patient navigation requires extensive duties performed in these particular domains, supporting the need of an individual with a specific role who can provide time and attention to perform these duties to insure navigation.

An example of the relationship between one navigator’s activities and the number of patients for whom a novel navigation attempt was made is exhibited in Figure 1. Concordant spikes in activities, such as communicating with Ryan White services, making navigation related telephone calls, and navigating patients into harm reduction occur during time periods in which a novel navigation attempt was made (novel navigation attempts are represented by black squares in Figure 1). These data highlight the importance of the navigator role, where having a designated staff person serve the role of navigator can help the navigation process.
Figure 1. Example of navigator activities and number of new patients for whom a navigation attempt was made

Qualitative findings: Patient navigators

Semi-structured interviews were conducted with the 4 patient navigators who were involved in the program. Navigators talked broadly about their experiences with patients, the program, the clinic, and their role as navigators. Several emergent themes were identified in the interviews, including: time spent conducting outreach activities, testing clients for HIV, the process of recruiting clients into care, population-specific problems regarding drug use and navigation into care, challenges acclimating to patients’ needs, actively coordinating with Ryan White Services points of contact, the patient navigator facing challenges in the role of navigator, the navigator referencing or using his/her personal history to improve the navigation process for clients, working with clients on medication adherence, extensively communicating with clients, teaching clients, instances of clients exhibiting behavior change, and strategies to retain clients in care.

Conducting outreach

By extensively engaging in outreach activities, patient navigators were not only able to build relationships and trust in the community, but were able to identify and begin attempts at
recruiting people living with HIV/AIDS (PLHA) into care.

In order to identify venues for outreach, patient navigators described asking clients where they hang out. In some circumstances, navigators intentionally changed their style of dress/appearance to appear less conspicuous and to reduce social distancing with potential clients when conducting outreach in communities. Outreach venues were broad and included outreach vans conducting syringe exchange, church activities, talking to potential clients at health fairs, and even traveling to jails to teach overdose prevention. Harm reduction sites which had outreach vans were successful in making a large number of community contacts, particularly with drug users in the community. Navigators reported challenges in identifying new venues (from the ones they were already engaged in), and noted that the police can be a deterrent for potential clients in the context of conducting outreach in vans.

Outreach was described as a particularly important and key activity for navigators, as it may be the only time and space in which HIV positive drug users were making contact with any component of the healthcare/medical system. Thus, patient navigators’ high levels of knowledge, professionalism, and open communication regarding drug use in the context of harm reduction – for heroin in particular – served as a potential bridging mechanism into care for drug users.

In addition to outreach activities where the peer navigator leaves the harm reduction site to interact with clients in the community, several clients eligible for navigation were identified through syringe exchange programs affiliated with the harm reduction site. The time spent conducting syringe exchange, while brief, provided navigators with opportunities to discuss HIV status and testing with clients, and to identify clients that are not receiving care. During syringe exchange, some navigators conducted HIV tests with drug users.

Navigators recognized the importance of their roles, and when the organization allowed them the flexibility to act as navigators, they were able to achieve more effective outcomes with clients. One navigator reiterated that

“…it is very important for the patient navigator know their roles...if you establish an idea of know what you have to do, and somebody else tries to go into your role doing the incorrect thing, it doesn’t work...it’s very important so that everybody knows what everybody has to do...we are a team...everybody is a support system...it is very important because it is serious. It is serious and it’s not easy.

In this regard, navigators with a specific focus and set of job responsibilities were able to successfully recruit and navigate clients into care in a relatively short time span.

Recruitment into care

In some circumstances, clients that were identified through outreach activities did not know their HIV status, and in other instances they did know their status but were not receiving treatment. Recruiting a potential client into care can be laborious, as indicated by the following experience one navigator described with a client:
I identified the client in my church...and he disclosed his status...I said “Oh you are in care?” And he said “well yes...”, but I’ve never seen him...so I said “oh when was the last time?” And he said 2007. ...it is in that moment I provided my information and said I work there, and that he would show up the next day that I told him. And the next day...he didn’t show up...we went to talk to him. We went to three different addresses he gave us, but we have some information in CareWare, and we went to that house and he was there, and then he was allowed to come.

Navigators described difficulty in getting clients to make an initial appointment to obtain Ryan White services. Oftentimes, navigators described that it was difficult to capture clients upon meeting them, and that “forcing” a client into care was a futile attempt, and that if a client did not want to go to the clinic, the client would easily be lost. Thus, navigators described engaging in extensive pre-visit communication with clients as well as using motivational interviewing strategies – communication that was aimed at recruiting clients living with HIV into care. As one navigator described:

Usually...if you don’t catch them at the time of testing, and they’re told that they’re positive, there’s a real good chance they’re going to run straight to the land of denial...and forget. They need somebody to hold them and say ‘Look, it’s going to be alright. We can fix some of this today. Everything not going to be fine, but you’re not going to die today. It’s going to be alright.’ ...Try to smooth out those bumps immediately because they just become mountains after awhile.

In cases where the patient already knew their HIV status, the communication often involved finding out the specific reasons the client was not engaged in care, and then addressing those factors with the client to engage them in care.

Once a client agreed to an appointment, navigators described working with Ryan White case managers and staff to “fast track” clients into care. Navigators described working on a rapid timeline, directly communicating with the Ryan White point of contact as well as the navigator’s own network with the clinical community (which also involved office staff at the clinic), and finally, the navigator accompanying the client to the initial appointment. Accompanying clients to the initial appointment was particularly important, as this is a time when potential clients may become frustrated or nervous in the waiting room. There were several instances where a client’s behavior or disposition toward the clinic may have resulted in the patient leaving or being kicked out of the waiting room had the navigator not been accompanying the patient.

Further, navigators often directly addressed material barriers to accessing care for clients. For example, navigators often ensured that adequate transportation for the client was available, and in some circumstances the navigator actually drove the client to the appointment. Further, navigators often spoke with clients about concerns regarding medical insurance and how the appointment would be covered. In other circumstances, navigators described helping clients with paperwork, not only for insurance, but also for completing other forms regarding welfare receipt and food stamps. One navigator described the following:
If I find somebody that has been diagnosed for two years but...hasn’t been in care for the last two years...I get to ask why, and find out what’s going on with their personal life - to find out why they aren’t getting care. Is it medical insurance? Is it housing, health care, ignorance...lack of care? Where does he live? Does he have transportation to get to the clinic?...What does he know about the virus? There’s a bunch of issues that I have to explore even when engaging a new client that is even thinking about getting into care, I need to find out their level of knowledge about the virus before I can even go any farther with them.

In almost every circumstance of navigation, the navigator waited with the patient in the waiting room prior to the appointment. The presence of the navigator during this period was particularly important, as many clients could become ambivalent about seeing a doctor or waiting for the appointment itself. The presence of the navigator thus helped keep client appointments, particularly first time appointments.

Troubleshooting client problems

Navigators reported several problems experienced with clients keeping their appointments, particularly problems revolving around lack of access to material resources which impact healthcare accessibility, problems surrounding HIV status, and problems surrounding current drug use.

Given that most clients navigated (or for whom a navigation attempt was made) were active drug users, it is not surprising that drug use emerged as a typical problem encountered during the navigation process. This included clients focusing their financial resources, attention, and time on obtaining money in order to purchase drugs, clients engaging in excessive drinking, clients using heroin to function (or to “stay well”) and prioritizing heroin, homelessness and transient living circumstances, drug use inhibiting willingness to receive treatment, and clients slipping back into heavy drug use and missing appointments.

Particular issues surrounding client HIV diagnosis included the client being concerned about disclosing HIV status to a current partner, disclosing HIV status to family, and clients remaining in denial about their HIV diagnosis.

Particular issues surrounding access to material resources including client inconsistency with filing forms for food stamps and housing, clients not responding to telephone calls, and clients attempting to obtain work and missing appointments due to work. Finally, one of the major issues which persistently emerged was that clients tended to maintain a focus on obtaining money and using heroin, and it was thus a challenge to work with clients to address their healthcare needs.

In addition, patient navigators reported challenges in workloads, compiling clients’ paperwork, concerns about clients’ comfort levels in working with the navigator, taking a harm reduction clients' unresponsiveness personally (particularly with regard to scheduling appointments). In order to overcome several of these challenges, navigators broadly described strategies to acclimate to the particular circumstances of individual clients, particularly those who were not proactive and those who did not express initial interest in accessing care for HIV. Building a professional disposition as a navigator with active drug users was described as a
difficult process. Client trust and complacency regarding care were barriers to building a relationship with the navigator. However, navigators described using strategies such as persistence in communication attempts, increasing availability to the client, and staying open-minded during interactions to accommodate clients’ psychosocial hesitations regarding HIV care. Overall, navigators described attempts at being a reliable, trustworthy, and down-to-earth person that clients could rely on when they needed to access services.

Navigators reiterated that fast-tracking patients into care was of utmost importance, particularly when harm reduction clients were willing to attend an initial appointment. Navigators and Ryan White points of contact kept regular communication regarding new patients and the status of current patients. The process for navigators to contact case workers at Ryan White sites was streamlined, and having one designated point of contact at the clinic was described as helpful for navigators in increasing speed and accessibility of services for clients.

**Using personal history and experience to inform navigation**

Harm reduction and patient navigation are two distinct concepts that were described as not being immediately complimentary. In the context of syringe exchange, harm reduction may require a more “passive” approach from a harm reduction specialist, whereas navigating a patient requires a more active approach on behalf of the navigator. For individuals attempting to serve both functions, time and training were required. As one navigator describes:

> …especially from...a harm reduction approach...we want them to bring up the conversation or treatment options and then we give them resources whereas in this model, it’s kind of us saying “well there is treatment out there- are you ready to get into treatment? This is what we can provide for you”... it’s way more direct so it’s definitely different because [in] harm reduction, you don’t want to be pushy, you don’t want to push them away but in this sense you have to be very strategic in your motivational interviewing and what words you’re using and how to bring them in...so I think for that, and for me I would like to expand on my motivational interviewing skills so that I can be more strategic in my patient navigation skills on a harm reduction out reach. You know, not just with HIV/AIDS care but in treatment and in housing...So I think that this model can be really effective in harm reduction if you learn what kind of language to use ...

Thus, stepping into the role of patient navigator role could mean that a harm reduction specialist take a different approach with a client regarding their HIV healthcare seeking behavior, but not with regard to their other health behaviors, where a low threshold of change was negotiated.

In many cases, navigators drew upon their personal experiences with drug use, at-risk populations, and knowledge of material restrictions in order to better facilitate the navigation process. From the perspective of harm reduction, patient navigation can be a much more “invasive” process, where the navigator needs to be prepared for pitfalls before they arise. Repeat telephone calls and client-by-client tracking with rapid follow-up is required to ensure that patients arrive at the clinic and maintain their appointments. In many cases, navigators used personal experience and history to inform the way in which they would approach difficult clients, with the expectation that recruiting and retaining clients in care would be a difficult process.
In particular, patient navigators’ past experiences with drug use and drug using individuals helped inform their current strategies as navigators. Navigators described foreseeing problems with particular clients and taking preemptive measures to avoid losing clients. Oftentimes, sharing a degree of personal information or experience with clients helped navigators gain legitimacy in the eyes of clients they were navigating, and helped the navigator obtain more personal information on the client. Navigators worked extensive and irregular hours, and exhibited a degree of discretionary effort which was often driven by personal motivation and experience. Navigators discussed how their personal experiences lead them to make HIV and drug use a personal issue, and helped motivate them in their current roles as navigators.

In developing rapport with clients, navigators were able to communicate about issues which may be difficult for clients to speak about with healthcare providers during brief clinical encounters. Navigators were able to communicate with clients on a more personal level and to engage them in motivational interviewing. As one navigator described:

Well if they are focused on [drugs], I focus my approach on their health. For me it is very important and I want them to be healthy. I talk about [how] there are people out there that love them- they need them- so they have to be healthy. If they get sick, if they don’t have a good relationship with the people around them, they are going to be in trouble- that is my focus point.

Navigators reported instances of being able to console frustrated clients, helping clients realize that others in their lives love them, increasing client comfort in order to obtain more personal information which would improve that patient’s navigation process, and of instances where the navigator had to draw boundaries to limit emotional connections with clients.

Navigators cited several challenges and successes in getting clients to increase their communication so as to better inform the navigation process. This involved finding out where and how the client gets access to basic material resources (such as food or housing), to understanding why a client felt distrust in the medical system. Navigators recognized that while telephone calls were useful, communicating with clients in person was a more effective communication strategy, and oftentimes navigators made attempts to meet clients in person to better facilitate communication and dialogue, resulting in improved navigation attempts. Navigators cited trust as an important element to build with clients that would improve recruitment efforts.

Retention in care

Following recruitment into care, navigators worked with clients and Ryan White coordinators to retain clients in care as part of the navigation process. Navigators and points of contact at the Ryan White clinical service location kept track of patient visits using a patient tracking form, indicating whether the client came to the scheduled appointment. Further, ongoing communication regarding patient appointments helped to establish regular communication patterns between Ryan White points of contacts and navigators. The link between the contacts was usually a novel development resulting from this pilot project. As one
navigator described:

*I didn’t have a contact at [the clinic], so that if I did come into contact with someone who was HIV positive I couldn’t just go in and be like “oh I know so and so and you can get in with them.” But now, it’s really been very great that I have this contact there that I can call whenever I know that someone needs services or I am just trying to follow-up on something. And she is so quick to respond. This is really a great thing that we have been able to establish...I feel like I have built a little bit of a rapport-it’s nice to have that bridge.*

In the case of missed appointments, navigators described client circumstances such as heavy alcohol consumption, “disappearing” at the beginning of the month when money is available (for drug use), lack of transportation to an appointment, work schedules, and/or losing communication with a client surrounding the time period in which an appointment was supposed to occur. One preemptive measure that navigators often took was to precede appointments with several telephone call reminders to ensure the client would be available, and that the client was able to access the appointment.

Navigators reported engaging in activities above and beyond telephone reminders for appointments. Navigators reported arranging transportation for clients with limited access to transportation, and when visits were missed, some navigators reported [physically] searching for clients in houses and/or motels where they may have been known to be located. Sometimes, a navigator might use community contacts to locate a patient. Navigators often had to take extensive measures with each client to ensure that they were tracked. As one navigator described:

*I make sure I know of all of their appointments. I call them each and every week. They are welcome to come in and talk to me about anything. I stay in contact with them. I offer them food and pantries here. I give them a reason to see me to come to stay in contact with me...Bus tickets. You know I need a valid address. I need a telephone number you can be reached at. I ask for a landline of a family member...things like that...real simple stuff. Give them what they need...hook ’em up with issues like housing. Make them stable. Transition no more...Invite them to a group to talk about feelings about being HIV positive. Especially the newly diagnosed. There’s a lot of emotions going on in them...you know?*

Following appointments, most navigators remained in contact with the client to ensure that follow up care was being met. Oftentimes, this involved speaking with clients about adherence to their prescribed medications. Navigators would speak with clients about their routines for taking medication, and some advised clients on how and when to take medication. Medication adherence is a complex issue, and the navigators could serve as a sounding board and knowledge provider regarding the importance of remaining adherent to proscribed medication. There were even instances of navigators accompanying clients to pharmacies in order to pick up their medication and to ensure that clients understood how to take medication.

Harm reduction models call for low thresholds of behavior change, and in drug users,
harm reduction tends to call for safer drug use practices. However, patient navigators described behavior change in clients that were navigated into care. This involved navigated patients becoming actively involved in harm reduction classes, clients bringing in a higher volume of syringes for exchange, clients engaging in secondary exchange, clients expressing interest in learning more and expressing interest about getting into clinical services for HIV, clients being able to go to and keep appointments on their own in the absence of the navigator, and clients seeking additional forms of treatment. As one navigator described:

*I keep it real with them...I tell them ‘I can’t solve everything today, but we can solve some things in a short period of time.’ I make short-term goals for them. They call me. I praise them- let them know that they’re doing good.*

Indeed, while patient navigation does not reduce drug use, it ultimately compliments the positive effects of harm reduction by increasing clients’ accessibility and use of services to address their HIV infection.

**Qualitative findings: case managers (Ryan White clinical service points of contact)**

Navigators’ points of contact associated with sites providing Ryan White services often identified as case workers, and readily recognized the importance of the navigator in client recruitment and retention, and described ongoing communication with navigators regarding specific clients, as well as the process of fast tracking a client into care.

Case workers reiterated that it was important to make the process as “seamless” as possible for the patient, and reported working with the navigator to troubleshoot issues ahead of time, such as insurance issues or problems with identification that may result in incomplete form processing, so that when the client did arrive at the clinic for a scheduled appointment, the appointment went smoothly and the client had a positive experience. One case manager described the following:

*The navigator made sure the patients were seen quicker. The navigator’s patients were seen quicker...any kind of obstacles that we could take care of before, the navigator actually brought them in...we usually took care of. For example...to get seen...we have to make sure that, if they had an insurance issue and where they had to get a referral, we would talk...ahead of time and make sure that was taken care of. So when the patient walks in our door, they almost can come and see us. There were actually several instances were that happened. There are patients with different issues...If they had walked in off the street without coming in with a peer navigator they would have probably been stopped and told “You have these insurance issues. Um, You have to be able to...” And so it’s kind of seamless, at least I felt it was from the navigator’s patient. We did the best that we could make sure it was.*

Case workers noted the extensive work that navigators did prior to the client’s first visit. This included proactive communication, giving adequate notice to the case worker before coming into the clinic with the new patient. Further, case workers noted that navigators made attempts to make sure their patients were seen quicker, that navigators often provided transportation
assistance for clients to arrive at the clinic, and that navigators assisted clients with paperwork to ensure they easily got past front desk registration. Further, case managers highlighted that it was helpful that the navigator remained with the client, particularly for the first appointment with the case worker. In the case that the patient had additional questions, the navigator’s presence and familiarity with the client was described as being helpful, particularly during the initial intake appointment.

In addition, case managers reported extensive and ongoing communication with navigators regarding a patient’s care. As one case worker described:

_The peer navigator... is everywhere in the community-at the kitchen where they serve homeless people food, at drug rehab programs testing on site. So we communicate a lot...and we do see each other...we communicate on a daily basis as far as who’s out of care and who needs to come in and things like that ...we have a good connection._

Oftentimes, communication between the navigator and case worker involved troubleshooting specific issues to make sure a patient did not miss appointments, and for both parties to share details which might help the other improve the clients care.

Case workers typically worked in multidisciplinary healthcare teams, and acknowledged that the navigator’s assistance greatly enhanced the recruitment and retention of clients in care as part of the team process. Case workers described limitations on their amount of time, and could not always trouble-shoot specific issues that would arise with drug using clients, ranging from behavioral issues in the waiting room to follow up for missed appointments. In this context, the navigator was able to assist with “filling in” these gaps where a case manager might otherwise “hit a wall” with a particular client. One case manager described the following with regard to the introduction of the patient navigation program:

_I think the idea is great. With the one client who has been a little difficult to get into care-we’ve had a couple of appointments scheduled and for one reason or another, the client hasn’t been able to complete the appointment. The client did come in to see the provider...and he has another appointment to come back and talk about restarting medications. Most of my contacts have been with the patient navigator, I give the navigator credit for being the one who initiates contact more with me then the other way around, but that makes sense in that the navigator is the one who’s working with the clients and trying to navigate them into care. I think the model is great._

Ultimately, case workers at sites providing Ryan White clinical services viewed patient navigation as an added benefit, particularly in working with clients from a population subtype that were typically difficult to recruit and retain in care.

**CONCLUSION**

The evaluation of this project used qualitative and quantitative data to evaluate a pilot program linking clients of harm reduction services with Ryan White clinical services. The navigator role is one that requires a great deal of responsibility in identifying, recruiting,
retaining clients in care. The population of clients who actively use drugs can be difficult to
recruit and retain in care, and the presence of a navigator who could respond to the unique life
circumstances of this population resulted in several clients being successfully navigated into
care. Multiple tasks were required to sustain navigation, and utilizing a specified patient
navigator to link harm reduction clients with Ryan White clinical services shows initial evidence
that this model may be a promising practice to improve issues surrounding healthcare
accessibility among HIV positive drug users.
Patient Navigator - Newark: client navigation into Ryan White by week

Number of clients for whom navigation was provided into Ryan White services

Week
Patient Navigator - Newark: number of new clients navigated into Ryan White

Number of new clients for whom navigation was provided into Ryan White Services

Week
Patient Navigator - Newark: number of times navigation provided into Harm Reduction

Number of times navigation into Harm Reduction services was provided

Week
Patient Navigator - Newark: number of community contacts

Number of Community Contacts

Week
Patient Navigator - Newark: number of telephone calls
Patient Navigator - Newark: number of unduplicated clients served

Week

Number of unduplicated clients served

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5

1 3 5 7 9 11 14 16 18 20 22 24 27 29 31 33 36 38 40 42 44 46
Patient Navigator - Newark: number of clients education was provided

Number of clients for whom education was provided

Week
Patient Navigator - Albuquerque 2: number of community contacts

Number of community contacts

Week
Patient Navigator - Albuquerque 2: number of new client orientations

Number of new client orientations conducted

Week
Patient Navigator - Camden: number of new clients navigated into Ryan White

Number of new clients for whom navigation was provided into Ryan White Services

Week

1  4  6  9  13  15  19  20  21  22  25

0  0.5  1  1.5  2  2.5  3  3.5
Patient Navigator - Camden: number of times navigation provided into Ryan White

Number of times navigation into Ryan White services was provided

Week

1 4 6 9 13 15 19 20 21 22 25
Patient Navigator - Camden: number of times communicated

Week

Number of times communicated with Ryan White services point-contact person
Patient Navigator - Camden: number of times navigation provided into Harm Reduction

Number of times navigation into Harm Reduction services was provided

Week
Patient Navigator - Camden: number of community contacts

Number of community contacts

Week
Patient Navigator - Camden: number of new client orientations

Number of new client orientations conducted

Week
Patient Navigator - Camden: number of unduplicated clients served

Week

Number of unduplicated clients served
Patient Navigator - Camden: number of clients education was provided

Number of clients for whom education was provided

Week

0 0.5 1 1.5 2 2.5
1 4 6 9 13 15 19 20 21 22 25
REFERENCES

1. Miller PG. Safe using messages may not be enough to promote behavior change amongst injecting drug users who are ambivalent or indifferent towards death. Harm Reduct J. 2009;6(18).


