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The moral discourse of HIV providers within their organizational context: An ethnographic case study

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Abstract

Objective: Providers make judgments to inform treatment planning, especially when adherence is crucial, as in HIV. We examined the extent these judgments may become intertwined with moral ones, extraneous to patient care, and how these in turn are situated within specific organizational contexts.

Methods: Our ethnographic case study included interviews and observations. Data were analyzed for linguistic markers indexing how providers conceptualized patients and clinic organizational structures and processes.

Results: We interviewed 30 providers, observed 43 clinical encounters, and recorded fieldnotes of 30 clinic observations, across 8 geographically-diverse HIV clinics. We found variation, and identified two distinct judgment paradigms: 1) Behavior as *individual responsibility*: patients were characterized as “good,” “behaving,” or “socio-paths,” and “flakes.” Clinical encounters focused on medication reconciliation; 2) Behaviors as *socio-culturally embedded*: patients were characterized as struggling with housing, work, or relationships. Encounters broadened to problem-solving within patients’ life-contexts. In sites with individualized conceptualizations,

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providers worked independently with limited support services. Sites with socio-culturally embedded conceptualizations had multidisciplinary teams with resources to address patients' life challenges.

Conclusions and Practice Implications: When self-management is viewed as an individual's responsibility, nonadherence may be seen as a moral failing. Multidisciplinary teams may foster perceptions of patients' behaviors as socially embedded.

Keywords

Ethnography; Qualitative methods; HIV; Healthcare organization; Morals; Discourse; Communication

1. Introduction

Evidence-based medicine means that clinical decisions entail the best external evidence (i.e., data driven information), clinical expertise (i.e., the "art" of medicine) and patient preferences [1]. Clinical decisions should be informed by medical evidence and providers' knowledge of patients' unique contexts and abilities. Providers, however, often make judgments and decisions about care based on their beliefs about patients' characteristics, motivations, behaviors and perceived ability to self-manage. Borvoy et al. [2], for example, found that assumptions providers had about their patients influenced how they approached treatment planning, while Fineman [3] examined how providers use the concept "non-compliance" to demarcate unacceptable patient behaviors.

Determining the best care plan can be difficult, and risks becoming intertwined with biases. Decisions can unintentionally be based on patient characteristics, extraneous to care. Research has demonstrated how implicit biases based on patients' race [4–6], weight [7,8] or HIV status [9] can affect care. When judgments go wrong, they can undermine the patient-provider relationship [10]. Limited work has examined what may underlie provider conceptualizations of patient motivations and self-management behavior [2,3], yet how providers understand their patients may have important implications for care.

Provider conceptualizations may be especially important for conditions where adherence is crucial and social challenges common, as in HIV. The history of HIV is a history of blame, stigma, and marginalization. Patients with HIV have historically been stigmatized, even by healthcare providers themselves. In the early days of the epidemic, patients were blamed for their disease due to their 'immoral behavior' as HIV/AIDS was associated with homosexuality and intravenous drug use [11]. Despite external, clinical evidence, the practice of evidence-based medicine for patients with HIV may be hindered, consciously or unconsciously, by this history. Providers might subconsciously absorb and perpetuate these messages in clinical interactions. Patients may not be in a position to respond, given the power dynamics between providers and patients.

Additionally, and particularly for stigmatized populations [12], the organizational context may affect quality of care [13]. A review of the limited literature on moral judgment suggests the organizational context may be an important aspect of how patients are judged

[14]. Moreover, the organizational context of HIV clinics has changed. As HIV has transitioned to a chronic disease [15,16], with more effective antiretroviral therapy [17], HIV clinic structures have evolved [18]. Historically they provided integrated, multidisciplinary care because of the complexity of patient management, dominance of HIV-related medical issues, and stigma. More recently, while some care for patients with HIV is provided purely in HIV specialty clinics where all patient needs are attended to by a multidisciplinary team, others receive only HIV related care in the specialty clinic and get the majority of their needs met in primary care [19].

The question arises as to whether the different types of care organization for this marginalized population might shape providers' conceptualizations of their patients. We therefore sought to understand how providers conceptualize patients with HIV and how these conceptualizations are situated within specific organizational contexts. We examined data from a larger ethnographic study of HIV care, with three goals: first, to characterize how providers who care for patients with HIV conceptualize their patients; second, to examine the clinical context in which providers care for patients; third, to examine how provider conceptualizations are situated within different organizational contexts.

2. Methods

2.1. Study design

We conducted an ethnographic multiple case study [20] examining the provision of HIV care in infectious disease clinics at eight geographically-diverse Veteran Health Administration hospitals. We initially sought to learn about the organization of HIV care, through site visits. Sites were selected based on quality of care metrics for HIV and common co-morbidity outcomes [21,22]. Our ethnographic fieldwork focused on the organizational "structures," such as staffing and where patients received non-HIV care, and "processes," how teams worked together and the presence of patient-centeredness. All study procedures were approved by the Bedford Institutional Review Board.

Consistent with our ethnographic approach, a further exploration of the moral language of providers was motivated by an incidental finding. An interview question about the structures around prescribing Pre-Exposure Prophylaxis (PrEP), which reduces the risk of contracting HIV, generated a surprisingly judgmental response. The MD stated patients who wanted PrEP were "stupid" and he linked seeking PrEP with promiscuity and unprotected sex. He reported that another provider at this site refused to prescribe PrEP because it promoted sex.

In our overview fieldnote from the site, we went on to characterize the clinic culture:

Overview Fieldnote, Site 3—We were surprised by the tone and cultural climate of the clinic. The former head was dismissive, condescending towards patients, and divided people into two categories: "good people" and "stupid people." … in conversations [the lead clinician] also seemed to divide people into two categories: "compliant" and "disasters." In both cases, "disasters" and "bad people" were blamed for their non-compliance which seemed to be associated with moral failure rather than circumstance, context, or quality of care.

This led the two anthropologists on the site visit (GF, JH) to explore this phenomenon more thoroughly, using a *discursive reflexive* approach [23]. The use of judgmental language prompted us to think about the relationship between language and culture.

2.2. Participants and recruitment

Participants included HIV providers and their patients. Clinic section chiefs were identified from a national registry. At the 8 study sites, we requested a list of the HIV providers, whom we emailed describing the study and requesting participation. We mailed requests for participation to patients who received care at the clinic, in advance of our site visit. Patients were also recruited on-site via information sheets.

2.3. Data collection

Teams of 2–3 researchers conducted 2–3 day site visits between April 2016 and June 2017. Data collected included provider interviews, observations of clinical encounters, team interactions and informal clinic processes (see Table 1 for details).

2.4. Analysis

First, the lead author (GF) reviewed all interview transcripts and fieldnotes (see Table 1), looking for linguistic markers indexing how clinicians talked about patients. All data containing evidence of recognizable positive or negative references to adherence, self-management or morality/moral behavior were brought to the full team. We employed a reflective analytic process to work through this data using Carbaugh et al.'s [23] analytic processes, by *descriptively*, *theoretically* and *interpretively* examining each site's data. Consensus was obtained regarding the categorization of the characterizations.

Second, the eight member qualitative team examined the site's organizational context using a priori and grounded coding categories related to structures and processes of care [24]. Through data review and discussion, we categorized each site by their team-based interactions and whether treatment planning incorporated social determinants or psycho-social aspects of patients' lives versus purely adherence-focused planning. Interactions were categorized as Low (interactions primarily surrounded instrumental clinical tasks) to High (active engagement in formal and informal discussions about individual patients, across multiple team members). Information about patients' lives included elements of their daily-lived experiences, such as work routines, housing or their relationships with others [25]. We jointly coded Site 1 data. The remaining seven sites were coded in teams of 2–3, with at least one person who did the site visit. The full group discussed any questions. Syntheses were generated for each site to facilitate across-site comparisons.

Finally, we examined the language used and conceptualizations reflected in how providers talked about patients, within the context of the site's organizational characteristics. Sites were *systematically* compared[23].We sought counterexamples at each site, to ensure language was consistent across providers.

3. Results

3.1. Sample characteristics

We conducted 30 provider interviews, observed 43 clinical encounters, and recorded 30 additional observation fieldnotes. Table 2 provides more detail about the sites and the data collected.

3.2. Overview

Across sites, we identified contrasting ways in which clinicians conceptualized patients. In some clinics, patients' behaviors were viewed as an *individual responsibility*. In these instances, patients were described as "socio-paths," "flakes," "twits" or "good." These clinical encounters focused on medication adherence, with limited discussion of patients' lives. In the other clinics, patients were seen as *embedded within their socio-cultural contexts*. Patients were described as "fabulous," "fun," and "lovely," but struggling with housing, work or relationships. Although these providers also described patients using personality characteristics, they did not attribute self-management to these characteristics. These clinical encounters broadened to problem-solving within patients' life-contexts. Markedly, conceptualizations were consistent among providers within sites. Below we further describe these conceptualizations, and then explore how they were situated within the organization of care within each clinic.

3.3. Behavior as individual responsibility

In 5 sites (1, 3, 4, 5, 6), there was evidence of clinicians conceptualizing patients as individuals devoid of social context; self-management was viewed through a lens of individual responsibility. Patients were characterized using moral language suggesting good people were adherent, while bad, morally fallible people were not. There was limited discussion about patients' lives during the clinical encounters. Self-management behaviors, like taking medications, were framed as what "good" patients do. We observed a clinical encounter where taking medications was explicitly linked with being good:

Fieldnote Clinical Encounter, Site 5

> The MD starts by asking patient "**Have you been good? Are you taking your medication?**" She does not wait for a response between these questions.
>
> The patient responds, "Yes."
>
> She says, "You've never missed?"
>
> Patient: "No."
>
> MD: "Never?"
>
> Patient: "No." – She asks this a few times, which comes across as either grilling him or not believing him.
>
> [The clinical encounter continues with a review of the patient's labs, including positive cocaine screening, followed by a medication adherence assessment.]

> MD: “You’ve always been a good patient.” “You’ve always done everything I asked you to do. You come every time, take your meds, I couldn’t ask for a better patient.”

In this example, the provider begins the encounter by asking if the patient has been good. This is followed by a limited discussion of medication adherence, where the patient denies missing his medications by simply saying “no.” Notably, the provider asks this question multiple times, as if to catch the patient. The fieldnote writer noted the tenor of the interaction by describing the grilling nature and provider’s seeming stance that the patient was a liar. The circumstances of the patient’s life and impact of active drug use on self-management were not raised. The encounter ends with the provider reminding the patient that he is always good because he does what the provider asks. Here, the clinician provides a moral judgment by defining “good” patients as compliant.

Another provider linked a high HIV viral load with bad behavior:

Fieldnote Clinical Encounter, Site 1

> Interaction begins with Dr. stating that in January there was a high viral load (6000). Tells patient he tried to call him but couldn’t reach him. He is concerned that the patient has developed resistance.
>
> Patient immediately says he’s taking his medications, that he carries them with him.
>
> MD asks, “Scout’s honor?”
>
> Patient: “Yes, scout’s honor”.
>
> [They go on to discuss: shoulder pain, genotyping to determine resistance, medications & next appointment.]
>
> Dr. asks: “Anything else?” “You behaving?”; “Trying to behave?” …
>
> After the patient leaves, I ask [the MD] if he thinks patient is taking his meds. He says probably not. He has **said a few times to me that the patient is flakey**. He shows me the patient’s viral load in the past – under 40 for quite a while and then the spike to 6000. Thus he believes the patient is not taking the medications.

The discussion about medication adherence is framed in terms of the patient “behaving,” and the provider asking the patient to declare a “scout’s honor,” language associated with talking to children. It is belittling with a sense of scolding an adult patient. After the encounter, the MD goes on to describe the patient as a “flakey” person who lies about taking his medication, as confirmed by the patient’s viral load. The discussion is limited to whether the patient is taking his medication. There is no discussion about the patient’s self-management behaviors in the context of his daily life, such as his medication-taking routines, possible challenges or why his viral load may have changed.

3.4. Patients embedded within socio-cultural contexts

At sites 2, 7 and 8, we did not find explicit judgments about patients as individuals. Rather, patients were repeatedly talked about within their social context. Patients were infrequently described using adjectives describing personal attributes; when adjectives were used, they were positive. Instead, patients' behaviors were viewed within the broader socio-cultural context. Clinical encounters included problem-solving around elements in patients' lives that might interfere with self-management, like housing, work, or relationships. In this first example, a Nurse Practitioner (NP) called a patient who missed his appointment:

Observation Fieldnote, Site 2

> NP is calling missing 9am patient to see what's up with him but gets "the number you are trying is unreachable" recording.
>
> She comments that many patients can't keep up with cellphone payments. Now she tries to call his sister but gets no answer. There are no recent labs for this patient.
>
> She says she will have to try to re-schedule him for September. He takes the shuttle from another site and may have missed it.
>
> "He's a lovely man who moved here from [other city]."
>
> "I need to get him in – he's doing pretty well with his HIV; I try to maintain the focus. I will probably call the [housing program] person he's in touch with. They always stay in touch with [the housing program]; he may have changed his phone number. They do home visits and they can get a new phone number when they check in with him. I know he made this appointment. I should probably start checking phone numbers to see if people have changed them."

This NP demonstrated she knew the patient as a person. She reports contextual information about the patient's life that may have interfered with his getting his blood work or keeping his appointment, including: difficulty paying his cellphone bill, dependence on public transportation, and utilization of a housing assistance program. She also notes other people in his life, including his sister and a caseworker. Non-judgmental remarks were not recorded; the patient was described as "a lovely man." Notably, she puts the onus on herself to check patients' phone numbers in advance of their appointments. This same NP talked about another patient as a "fabulous young man" who had recently married and wanted to conceive. Again, this is notable because discussing conception, despite being clinically appropriate, can be a taboo topic for patients with HIV given the inherent link to sexual intercourse.

At site 8, when an interviewer asked about a "fairly difficult patient" seen earlier, the MD actively avoided this non-judgmental language and instead talked about "meeting people where they are." Later he talked about the "marginal world" in which patients live. Another patient was described as somebody "who has been excluded by the economy and he feels stigmatized." In discussing a patient with poor adherence, this provider directly attributed it to the patient's life:

MD, Interview, Site 8

> I can think of one particular person who consistently misses appointments and walks-in. I'm glad to see him because he doesn't always have the greatest adherence to his – I think he doesn't always have the greatest adherence to his

> therapy, and you know, he's got a bit of a chaotic travel schedule. So he will up and go to [another state] for a few months.

Here, the provider links missing appointments, not with individual characteristics, but with the patient's travel. This moves the blame from the patient being a bad person, to understanding the ability to show up at an appointment within the patient's broader life.

In this next example, an MD described patients who drink or use recreational drugs:

MD, Interview, Site 7

> And you could argue, you know, some of the patients, I would say, you know, there may be another 5% that I think have substance use issues that they don't see as substance use issues. The people that drink more than they ought to, but still show up for clinic, still manage to take all their meds, still have an undetectable viral load. Or use recreational meth[amphetamine], which I'm vehemently opposed to, but those patients still manage to take their meds, show up for clinic. So, you know, you have to sort of divvy up the patients. So for us, the patients who have substance abuse issues is not the same number of patients who it's totally, completely impacting their care and I can't control their HIV.

This provider works to disentangle adherence and substance use and refrained from judging patients for substance use. Instead, she notes these patients show up for appointments and have their HIV controlled.

3.5. Team composition, interactions & conceptualizations of patient behaviors

The 8 sites varied in their organization, particularly in regards to the team. We identified two dimensions of clinic context: 1) who was present on the team and 2) the extent of interactions among team members. We defined degree of interactions across professionals as Low, Moderate or High. See Table 3, which shows team composition and how these professionals interacted with each other.

When we compared sites by team members and their interactions, we found that sites with Low or Moderate interactions also had providers who characterized patients as individually responsible for self-management; discussions were biomedically focused and devoid of social context. These providers worked independently with limited use of support structures or inter-professional colleagues. In contrast, in sites with High inter-professional interaction, providers' characterizations of patients was socio-culturally embedded. In these cases, providers engaged with their multidisciplinary teams and utilized resources to address patients' contexts, alongside biomedical needs.

4. Discussion and conclusion

4.1. Discussion

In our study, we noted variation in how HIV providers talked about and planned care for patients with HIV. On one end of the continuum was the framing of behaviors as a function of individual responsibility. The providers whose perspectives fell along the individual responsibility end of the continuum described patients in moral language reflecting positive attributes (being “good”) or negative – implying a moral failing. On the other end, behaviors were framed as a by-product of complex socio-economic environments. These providers focused on self-management behaviors and challenges adhering to care plans within the context of housing, employment, or other potentially destabilizing forces. In these conceptualizations, providers did not equate personal characteristics (e.g., being “fabulous,” “fun”) with behaviors.

People are often blamed for their predicaments. Bad people are seen as moral failures that are unwilling or unable to behave properly. This can be seen in how those who are overweight are characterized as making poor dietary choices. People living with HIV have similarly been blamed for their condition [11]. In our findings, non-adherent patients were depicted as willfully making poor choices. This is consistent with others who have linked non-compliance with moral failure [3] and documented how the clinical encounter is a space of moral judgment [26].

Our findings of moral judgment and individual responsibility may reflect broader, American cultural ideals. American ideals of responsibility, autonomy, individualism and choice have been identified by others within healthcare [2,14]. In a review of clinicians’ moral judgments, Hill linked these judgments to American values, particularly for poor patients, who are seen as individually blameworthy for their predicaments [14]. Similarly, Hunt describes how American neo-Pentecostalism, codified in the “health and wealth gospel,” connects good, pious behavior with good health [27].

We also found judgments informed care planning. The providers’ understanding of their patient as either individually responsible or self-managing within a larger social context, was related to how they interpreted the patient’s behaviors and informed subsequent interactions. When providers assume a patient’s viral load has increased because of an individual moral failing, it prohibits a full exploration about what else may be happening in this patient’s life contributing to poor health outcomes. A missed opportunity due, arguably, to moral judgment.

Such judgments occur often in the context of medical care. Jaye et al. identified primary care clinics as a location where moral economies play out, with patients rewarded for abstaining from morally suspect behaviors like drinking or smoking [28]. The HIV clinics we observed may be a microcosm of US culture; the 3 clinics in which patients were conceptualized as socially embedded represent regions of the US (large Northeast & West Coast cities) that are known for progressive social policies—perhaps representing an additional cultural layer informing how clinics function.

Our work raises an important question about how clinic cultures are created. We saw care planning happening within a context of what the clinic could offer. The sites that conceptualized patients within their contexts had social workers and mental health professionals actively engaged in care. Teams with greater representation of professionals who were equipped to manage socio-cultural issues also thought about and addressed patients’ socially situated barriers to self-management. The other sites relied on more traditional, biomedically trained professionals. This suggests the key ingredient is a multidisciplinary team. The presence of social workers and mental health professionals, and the ways these disciplines conceptualize and plan care might afford providers the opportunity to have different conversations with their patients. As Provenzano notes [29], caring for patients with complex social needs, such as substance use, can be scary for providers. Having a multidisciplinary team, ready to address patients' full range of needs, might free providers to have difficult conversations, knowing there are supports on the team. Providers are no longer opening Pandora's Box to be dealt with on their own. However, caution is needed not to relegate difficult conversations or attending to patient's psychosocial needs to specific disciplines [30].The full team can and should play roles attending to patients' full range of needs.

4.2. Conclusion

Like all of us, patients with HIV want to be treated politely, with respect, and understood as individuals, without being stereotyped [31]—critical components of patient-centered care. We found that when patients were treated as unique individuals—with varying work and home routines—providers were better able to attend to their unique needs, and thus provide patient-centered care. Our findings show that when providers do not attend to the individual, and instead pass judgments on the moral character of patients, they fail to provide patient-centered care.

Let us not replicate the problem by passing judgment on providers who care for patients with HIV. We posit that providers too, need to be thought of as people, within their socio-cultural context – the context of the clinical world in which they work. It is this organizational context in which providers worked in our study that appeared to foster different ways of conceptualizing patients. The morally judgmental language we heard may be a defense mechanism for providers who work without a supportive network. With limited ability to address patients' social challenges, these providers may circumvent patients sharing information by framing conversations to only solicit affirmations of adherence. In contrast, multidisciplinary clinics may be able to address patients' full needs, including housing, substance use or psychosocial issues.

4.3. Practice implications

Thus, our findings may have implications for how care is organized for patients with HIV. The organization must be structured to support providers to problem-solve as they work with often socially complex patients. Then, providers may be able to become more patient-centered and see their patients within their own socio-cultural contexts.

To that end, patients with HIV should be seen by multidisciplinary teams, which not only would provide more comprehensive care, but, according to our findings, may also create a patient-centered culture. In the absence of such a team, organizations may need to work harder to engage providers to refocus their care on understanding patients within their socio-cultural contexts. This may include trainings or cross-disciplinary conversations within the institution about these complex patients.

Moreover, interactions among multidisciplinary teams may foster perceptions of patients as multi-faceted persons whose behavior is not a moral issue, but rather is a logical consequence of their complicated living situations. Continuing to support multidisciplinary care teams for patients with HIV, at a time when HIV care structures are changing, may not only reduce moral judgment, but enhance care planning. And most of all, as Duggan et al. [32] remind us, treating patients as unique people is a moral obligation of all healthcare.

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Table 1

Data Collection.

Data	N	Method	Participants	Focus of Inquiry[a]
Formal, semi-structured, qualitative interviews	30 interviews	Audio-recorded & transcribed	Providers who care for patients with HIV	Structure: Composition of HIV Care Team. Process: Perceptions of patient-centeredness and approaches to care, perception of teaming, addressing challenges to management of HIV and comorbidities; cross-disciplinary care coordination.
Observations of interactions during clinical encounters	43 observations	Recorded in semi-structured, descriptive fieldnote	Patients with HIV & their providers during their clinical encounter	Structure: Composition of HIV Care Team & who sees patients during a clinical encounter. Process: Extent of patient-centered practices and approaches to care; if/how challenges to management of HIV and comorbidities are addressed; treatment planning; cross-disciplinary care coordination.
Observations of HIV team interactions during formal meetings and other clinic routines	22 fieldnotes	Recorded in semi-structured fieldnote	HIV team members	Structure: Types of professionals involved in patient care; medical care routines; presence of comorbidity care; if/how psychosocial needs are met. Processes: How professionals interacted with each other; if/how non-HIV related questions and conditions are discussed.
Observations of informal clinic processes not capture in other data	8 fieldnotes	Recorded in unstructured, descriptive fieldnote	Informal interactions between HIV team members with each other, patients, &/or the research team	Structure: Location of HIV clinic within hospital, space allocation, hours of operation, administration. Processes: How HIV care is organized within the larger hospital, including check-in and check-out processes, and administrative tasks.

[a] Descriptive data outside the foci were also collected to allow for novel, grounded information to emerge.

Table 2

Site Characteristics and Data Collected.

Site	Site Characteristics			Data		
	US Geographic Location	**Area**	**Estimated # patients with HIV in care**	**Total Provider (MD, NP, PA) interviews**	**Clinical Encounter Observations**	**General Observations (i.e., interactions & meetings)**
1	Northeast	Medium Urban	78	2	4	3
2	West Coast	Large Suburban	246	4	6	4
3	Midwest	Medium Suburban	200	3	3	2
4	South	Large Urban	869	5	3	2
5	South	Medium Urban	254	2	4	2
6	Midwest	Medium Suburban	169	6[a]	6	5
7	West Coast	Large Urban	400	4	5	4
8	Northeast	Large Urban	497	4	12	8
			Total	30	43	30

[a] Includes MD Fellow.

Table 3

Team Composition and Understanding of Patient Behavior.

Site	Team Composition						Degree of interaction across professionals	Provider conceptualiz-ation of the basis for patient self-management
	Providers (MD, NP, PA)	Nurses	LPN & Med. Support Asst.	Pharmacist	Mental Health	Social Work		
1	3	1	-	-	-	-	Low	Individual Responsibility
3	4[a]	1	-	1	-	-	Low	Individual Responsibility
4	6[a]	1	-	2	-	-	Moderate	Individual Responsibility
6	4[a]	2	1	1	-	-	Moderate	Individual Responsibility
5	2	-	-	1	1	-	Moderate (with dyads)	Patient/Clinician Dependent
2	4[a]	1	-	1	1	-	High	Socio-Culturally Embedded
7	4[a]	1	-	1	1	1[b]	High	Socio-Culturally Embedded
8	6	1	3	2	-	1	High	Socio-Culturally Embedded

[a] Site has training program.

[b] Plus 2 case managers from community-based program.