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## Avoidance, Meaning and Grief: Psychosocial Factors Influencing Engagement in HIV Care

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### Abstract

Although the introduction of antiretroviral therapy has rendered HIV a chronic illness, inconsistent engagement in HIV care by key populations limits its public health impact. Poor engagement in care is especially prevalent among vulnerable populations with mental health and substance use disorders. Beyond structural and health system considerations, psychosocial factors may present challenges to sustained engagement. We conducted a qualitative study using in-depth interviews with 31 primarily African American, urban-based individuals, many with past or current drug use and mental disorders, living with HIV. Participants identified several psychosocial barriers that detract from their motivation to attend appointments and take medication. These included mental distress or detachment over a lack of purpose in life; denial about the need to be engaged in care; insufficient trust in the efficacy of care or the health system; deaths of loved ones leading to bereavement or loss of social support; and engagement in specific avoidance behaviors like drugs and alcohol. The study findings suggest that more comprehensive HIV care, which integrates mental health and substance abuse services in order to enhance meaning and address coping and grief, may be important. Considering these services in addition to improving the logistical components of care such as cues/reminders, accessibility, and patient-provider communication may improve intervention packages.

### Keywords

HIV; engagement in care; drug use; mental health

### Introduction

Since the advent of combination antiretroviral therapy (ART), individuals adhering to treatment live longer, healthier lives and prevent transmission to sexual partners (Cohen et al., 2011). Adherence may also limit antiretroviral drug resistance, which is an increasing concern (Gardner et al., 2008). Despite the importance of treatment for decreasing HIV-related morbidity and mortality, in the United States only 40% of people living with HIV/

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AIDS (PLWHA) access HIV care and only 30% have achieved viral suppression (CDC, 2014). These rates are even lower among low-income minority populations and drug users (Dale et al., 2016; Thames et al., 2012).

Many interventions aim to increase engagement via cues to action, however evidence suggests that non-engagement is often influenced by factors unrelated to memory (Kalichman, Kalichman, & Cherry, 2017). Specifically, aspects of vulnerability which potentially impact engagement include race, socioeconomics and mental health status. Vulnerable populations experience greater health care need and simultaneous decreases in access to quality care (Grabovschi, Loignon, & Fortin, 2013). Interventions within vulnerable communities struggle with effectiveness (Mathes, Pieper, Antoine, & Eikermann, 2013; Parsons, Golub, Rosof, & Holder, 2007).

In the United States, PLWHA are two to seven times more likely to suffer from depression (Owe-Larsson, Säll, Salamon, & Allgulander, 2009). Those in HIV care report 12-month prevalence of alcohol use at 19% and drug use between 4–13% depending on substance, compared to 3% and 1% in the general population respectively (Hartzler et al., 2017; Merikangas & McClair, 2012). Drug and alcohol use negatively affect engagement (Braithwaite & Bryant, 2010; Dale et al., 2016). Many PLWHA live in poverty with competing demands for survival (K Hotta et al., 2007). Further, HIV diagnosis may lead to existential stress including questioning the meaning of life, anxieties around death and feelings of social and experiential isolation (Mayers, Naples, & Nilsen, 2005; Schönnesson, 2002). Poor mental health, drug use and poverty often predate diagnosis and affect PLWHA's access to and coping with their HIV status and related care (Holtzman, Brady, & Yehia, 2015).

Literature suggests that interventions to increase engagement in care show modest effects that wane over time; however, multi-component interventions may have superior, additive effects (Kanters et al., 2017). To create such packages, understanding how HIV care is negotiated among vulnerable PLWHA is needed. When facing the complexities of multiple hardships, patients may deprioritize HIV care in favour of more immediate concerns. Therefore, within a population of vulnerable PLWHA we sought to understand factors influencing engagement in care.

## Methods

This analysis represents a qualitative sub-study in a randomized pilot intervention called mPeer2Peer (Lam et al., 2016; Westergaard et al., 2017). The mPeer2Peer study was a pilot prospective, randomized trial comparing the effectiveness of a nine-month multi-component, mobile phone-based intervention to standard of care for intravenous drug users (IDUs) re-engaging in HIV care. The standard of care offered, but did not ensure that participants accessed case management services. The present qualitative investigation uses information, unrelated to the phone-based intervention, obtained from individuals in mPeer2Peer's control and intervention arms.

## Study setting and population

HIV-infected adults not currently receiving ART with a prior or current substance abuse disorder were recruited for mPeer2Peer in Baltimore, Maryland. Participants were eligible if they were 18 years or older, had a documented HIV RNA concentration of 1000 copies/mL or greater, and willingness to attend at least one HIV care visit at the Johns Hopkins Hospital Adult HIV Clinic. Recruitment was based on inconsistent engagement in HIV care, defined as reporting a lapse in ART of at least 6 months, and no clinic visits with an HIV care provider in the preceding six months.

A prior diagnosis of substance use disorder including alcohol, cocaine and heroin, was an inclusion criterion until the middle of the study when the criterion was removed due to difficulties in recruitment. Those actively using drugs were not excluded. Individuals with severe mental illness or participating in other studies were excluded.

## Recruitment into mPeer2Peer

Eligible participants were identified among those enrolled in the AIDS Linked to the IntraVenous Experience (ALIVE) study, a cohort study in Baltimore (Vlahov et al., 1991) and through outreach to patients with lapses in HIV care through the Johns Hopkins Hospital Adult HIV Clinic patient registry. Individuals who consented were randomized in a 1:1 fashion to receive treatment as usual, which involved standard HIV care, medical case management, other services offered in the clinic, and the mPeer2Peer intervention. Components of the mPeer2Peer smartphone application and peer health navigation strategy have been previously described (Westergaard et al., 2017).

Participants completed a baseline demographic form, and intervention arm participants completed an additional barriers and facilitators questionnaire developed for this study. Qualitative interviews were conducted either during the baseline visit or at a separate visit.

## Qualitative data collection and analysis

Thirty-one interviews were conducted using a semi-structured interview guide with open-ended questions related to engagement in care. Interviewers trained at the graduate level in qualitative methods reviewed questionnaires prior to interviews in order to assist in probing. Interviews were digitally recorded and averaged 36 minutes. Details on qualitative data collection and analytic methods have been described previously (Lam et al., 2016).

Interviews were transcribed, and transcripts were imported into MaxQDA for thematic qualitative analysis (MaxQDA: Release 11. Statistical Software. Berlin, Germany: VERBI Software). The analytic process included coding qualitative data, subsequent analysis and thematic mapping. A codebook was created to name and define each emerging theme, permitting theories and tentative hypotheses to emerge from the data (Braun & Clarke, 2006). Analysts held regular meetings to cross-reference codebooks and ensure that data was analysed iteratively.

The final codebook contained four major categories: (i) demographic characteristics, (ii) HIV diagnosis and treatment history, (iii) barriers to care, and (iv) facilitators of care. These categories were then analysed further and organized into relevant themes. Coding was

complemented by analytic memo-writing, which further developed the concepts identified. In the final iteration of coding, themes were fully defined and the transcripts re-read to verify significance and relationships between themes. Some of the ‘barrier’ and ‘facilitator’ parent codes had a ‘psychological and psychosocial factors’ sub-code. The ubiquitous nature of this sub-code, which emerged inductively from the data, warranted a discussion separate from that of the previously published article on health system related factors (Lam et al., 2016).

## Results

Participants consisted of 12 women and 19 men (mean age 49.8, SD=7.9 years). Approximately 90% self-identified as non-Hispanic Black; 80% had a history of cocaine or heroin use. Nearly one-third made less than \$2500 during the previous year and four-fifths made less than \$10,000. All participants had previously received HIV care, i.e., taken medication and/or attended a medical appointment at least once. Fourteen participants had prior psychiatric diagnoses and four were diagnosed during the study. The most common diagnosis was major depressive disorder followed by other mood disorders (bipolar disorder and major depressive disorder with psychotic features) and schizotypal personality disorder.

### “Sometimes I do forget, but most of the time...I let my feelings get in the way.”

Participants described how emotions sometimes interrupted their intentions to engage. *“Sometimes I do forget [medicine/appointment], but most of the time it’s the way I feel. I let my feelings get in the way, seriously.... Like my biggest problem is me really, really, really.” (62-year-old woman with history of drug use)* Other participants described discontinuation of ART as a deliberate decision, made with a clear understanding of the possible consequences.

I’ve been in a very dark place... See I didn’t take my medicines because I didn’t wish to live.... I was thinking, ‘How have I survived?’ Everybody else that I knew died, why was I still alive? .... I guess my thoughts was, ‘it could all be over, it could’ve all been over, all your pain would have come to an end. (45-year-old man)

In the face of such stress, some participants sought mental health services and found it helped their engagement. Reaching the decision to seek care was sometimes described as a “tipping point,” often arrived at by way of a triggering event.

[the depression] just grew and grew and grew and at that point the drugs grew and grew and grew. And then it just came to the point... I guess the reality of it... it made my mind snap, you know.... March, like I said, was the tipping point for me and that’s when I started being dedicated. (36-year-old man)

Underlying these discussions participants mentioned needing *meaning* and *purpose* in their lives, which alongside emotional distress represented the most ubiquitous theme. Work, attaining personal goals such as finishing high school, or raising children and grandchildren were described. One individual stated that HIV itself provided new meaning.

“Most human beings have a sense of being the best that they could be. But AIDS can kind of make you feel like it’s all over. So, if they can be made to see where

this is not an ending but maybe a beginning...They look at the illness as maybe a beginning of a new life where they can achieve things maybe that they couldn't before 'cause now they understand the things that they didn't before. (45-year-old man)"

**“Sometimes my appointments don’t be that damn serious... There don’t be shit wrong with me.”**

Besides emotions and meaning, over half of participants voiced distrust of treatment. Some believed medications did not improve their condition, or shared *“I don’t feel sick or nothing, you know. I ain’t that sick.”* In other cases, fatalistic attitudes framed their statements.

If it’s meant for me, I’m going one day. I ain’t gonna be around forever. I know y’all want me to take medicine and this will help. You know, I understand all that shit but right now I’m doing just fine. (45-year-old woman)

Among individuals with a strong reason to live, they saw medication as helping to achieve that goal. HIV care was seen as self-love, and trust in medicine was tied to historical experiences.

I do what’s best for me, because I love me.... I watched my grandmother die... from cancer. And all the technology that they have now they didn’t have then for cancer. So I try to support most of the technology that they have now .... One thing she put in me that always stayed with me, and I tried to put it in my kids, ‘No one can love you more than you can love yourself besides your parents.’ (55-year-old man)

**“If you have no steady support group [family] and nothing to work toward, why work?”**

Themes were often discussed in the context of relationships with others. A 36-year-old man stated, *“That was a hindrance ... ‘cause I had nobody to talk to or no support, like, you know, about my situation.”* Others described how unhealthy relationships could also adversely affect care. Deaths of loved ones were discussed by almost half of all participants. Both emotional mourning and the concrete business of making final arrangements were described as hindrances.

One person described emotional difficulties going to the clinic where she used to go with her now-deceased partner: *“There’s memories here for me from coming to the doctor with him.... Once the grief was more acceptable for me, I would come back. I just didn’t want to come right back after his death.”* (55-year-old woman)

Another patient described how the grieving process led to the emergence of depression, impacting his HIV care, *“My father died and I fell into like depression and you know, anger, you know.... And I just didn’t wanna do it [adhere to HIV care] no more.”* (36-year-old man)

**“You’re trying to numb yourself basically.”**

Substance use was perceived as an obstacle for some users, but not all. One man described, *“As long as I’m not using, I’m fine. My life is wonderful when I’m not using drugs.”* (49-

*year-old man*) Drugs and alcohol were a means of coping, “*You’re trying to numb yourself basically.*” Using drugs and alcohol gave a 36-year-old man a self-reported “*arrogance of ‘don’t care’.... ‘I don’t need it [the medicine] and I can make it without it.... I still look good, you know.*”

A man in his late forties described that the stress from a bad relationship could lead to heroin use, creating a feeling of not caring, which in turn would cause him to disengage from care. A 56-year-old woman said that after taking drugs she “*just didn’t want to go*” to the appointments.

**“It’s just me not wanting to do it, you know, or not facing what you have to face. Being in denial, I guess.”**

While substances were used to cope, denial was frequent. Patients immersed in drug use prior to HIV diagnosis found that substance use contributed to their state of denial.

So when I was told that [I had HIV] I was so caught up in the realm of my drug behavior I really wasn’t paying the HIV no mind .... I tried to sweep it under the rug. I just didn’t want to face the reality of dealing with that I have HIV. (52-year-old man)

Another individual described his denial as linked to a fear of death and his inability to face the disease.

I wasn’t interested in knowing my CD count ... ‘cause they say HIV leads to AIDS and then people say, you know, “You die from AIDS,” I was afraid that if I find out I got AIDS and didn’t know how to take care of it, I would pass away, so I wasn’t interested in knowing about my healthcare. (53-year-old man)

## Discussion

In this qualitative study of adults inconsistently engaging in HIV care, we found that poor mental health, a lack of will to live and grief over the losses of loved ones were contributing factors. Participants described grief as devastating and disruptive to their engagement in care. Lacking the will to live was sometimes offset by the creation of existential meaning. Negotiations with medications and the medical system related to patients’ empirical assessments of themselves as “fine”. Avoidance coping strategies such as substance use and denial were frequent.

Lack of meaning or purpose in life negatively affected motivation to engage in care. These have been referred to as “transcendence needs,” or the need to question meaning and find purpose after HIV diagnosis (Barroso, Leblanc, & Flores, 2017). This may surround goal setting, work, or familial obligations (Barroso et al., 2017; Mayers et al., 2005). While HIV is no longer life-threatening, it may disrupt one’s sense of control over life, leading to an “HIV-related crisis of meaning.” Anxiety about death, present in our results, may add to existential stress (Schönnesson, 2002). In a study of terminally ill cancer patients these questions about existential meaning, if unfavourably answered, contributed to a lack of will to live (LeMay & Wilson, 2008). Positive reframing and attention to the creation of meaning

and purpose in PLWHA's lives may increase engagement (Mathes et al., 2013). Peer support interventions may be appropriate for this aim (Simoni, Pantalone, Plummer, & Huang, 2007; van Leunen et al., 2017; Webel, Okonsky, Trompeta, & Holzemer, 2010).

Our participants described loved ones as both beneficial and deleterious to engagement. Social networks provide 'love and belongingness' and promote engagement through instrumental support and empowerment in autonomous decision-making (Barroso et al., 2017; Finocchiaro-Kessler et al., 2011). In the case of our participants, social networks also provided existential motivation, possibly explaining how grief exacerbated poor adherence. While generally a natural process that attenuates over time, 10–15% of individuals, especially those with low social support, experience prolonged and extreme grieving known as complicated grief, which can have cascading behavioural and therapeutic implications (Crunk, Burke, & Robinson III, E H Mike, 2017; Sluzki, 2016). Group coping therapy for bereaved PLWHA has shown modest gains and suggests that screening for complicated grief should be a component of HIV care (Sikkema et al., 2006). Those prone to complicated grief and extreme moods may also be prone to drug use, or other limiting coping strategies (Kuchinad et al., 2016; Valero et al., 2014).

Denial and avoidance coping strategies were frequently mentioned. This coping style may have alarming repercussions to health related quality of life (Surah et al., 2013). Denial and drug use may have reinforcing effects on depression (Fleishman & Fogel, 1994). That substance use relates to disengagement in care corroborates previous findings (Shubber et al., 2016), and while denial does not have a direct effect on engagement in care it may contribute in other ways (Power et al., 2003). Continuing study of co-located or concurrent care for substance abuse and depression is warranted (Dale et al., 2016; Guise et al., 2017). Avoidance may represent a lasting component of the illness experience and should be actively addressed during care (Telford, Kralik, & Koch, 2006). Interventions for substance use should identify motivations for use and teach coping strategies (White, Gordon, & Mimiaga, 2014).

Participants often perceived their own health as "fine". In a narrative study, HIV patients placed subjective meanings on treatment, meaning that if they "feel fine" without medication, discontinuing care is rational from the patient's standpoint (Wong & Ussher, 2008). Rationales aimed at diminishing treatment may also stem from side effects, trust in the medical system or quality of the doctor patient relationship (Gaston & Alleyne-Green, 2013; Kalichman, Eaton, Kalichman, & Cherry, 2017; Li et al., 2017; Sankar, Neufeld, Berry, & Luborsky, 2011). Reducing the burden of care on individuals who are otherwise healthy by negotiating the frequency of care requires further study (Ellman, 2015).

## Conclusion

This analysis provides insight into a marginalized group of patients historically difficult to engage in research and medical care. Although increasing evidence suggests that subjective rationales and experiences create the framework for engagement in care, interventions are often narrow (Shubber et al., 2016). This formative evidence suggests that beyond integrating substance use programs and mental health services, counselling should focus on

the creation of meaning in PLWHA's lives, target avoidance coping strategies, and address grief when necessary. Understanding how, and to what extent, provision of such support during HIV care affects adherence is an important domain for future study.

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