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Moving Toward a Novel and Comprehensive Behavioral Composite of Engagement in HIV Care

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Abstract

Suboptimal engagement in HIV care increases risk of HIV-related morbidity and mortality; however, a comprehensive and practical measure of engagement in care does not exist. The objective of our study was to identify and develop a composite of engagement in HIV care. From May through August 2013, we conducted a cross-sectional study of HIV-positive individuals who consented to participate in an online survey. Engagement in care was assessed by the following self-reported variables: 1) having attended an HIV health care provider appointment in the past six months, 2) reporting a scheduled future HIV health care provider appointment, 3) knowing their last CD4+ cell count, 4) knowing their antiretroviral medication names, 5) reporting ARV adherence≥80% on the visual analog scale (VAS) and rating scale, 6) reporting adherence≥90% on the VAS and rating scale, and 7) not having missed all antiretrovirals for at least four days in a row in the past three months. To create the Composite of Engagement in Care, the presence or absence of these variables were summed and categorized (7=“high engagement”, 5–6=“moderate engagement”, and 0–4=“low engagement”). We examined the correlation between this composite and self-reported HIV viral load (VL; detectable versus undetectable) in a logistic regression model. We surveyed 1,259 HIV-positive individuals; 85% reporting an undetectable VL and 67% reporting excellent adherence. Approximately 89%, 88%, and 67% of those with high, moderate, and low engagement, respectively, had an undetectable VL. Having moderate engagement was associated with 3.5-fold higher odds and high engagement was associated with 4.0-fold higher odds of virologic undetectability compared to low engagement (overall p-value<0.0001). Our data indicate that this novel and comprehensive composite of engagement may be a useful tool in clinical and research settings given its high correlation with virologic outcomes. Future research should validate this composite in other populations and examine it prospectively.

Keywords

HIV; adherence; engagement in care; continuum of care; retention in care

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Conflicts of Interest
The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Introduction

The HIV Medicine Association of the Infectious Diseases Society of America guidelines for the management of persons infected with HIV states that, “adherence to care not only means medication adherence, but also adherence with medical visits and engagement in care” (Aberg et al., 2014). Adherence to HIV care, also referred to as engagement in HIV care, includes the processes of linkage and retention in care. Delayed linkage and poor retention has been found to be associated with delayed receipt of antiretroviral (ARV) medications, higher rates of virologic failure, and increased morbidity, mortality, and HIV transmission(Berg et al., 2005; Giordano et al., 2007; Keruly, Conviser, & Moore, 2002; Lucas, Chaisson, & Moore, 1999; Mugavero et al., 2009; Park et al., 2007; Ulett et al., 2009).

There is no gold standard for measuring retention and engagement in HIV care(Mugavero et al., 2012). While studies of engagement in care have primarily focused on HIV care visits and used measures such as appointment adherence, missed visits, or visit constancy(Mugavero, Davila, Nevin, & Giordano, 2010), engagement in care is more than appointment attendance. A limitation in using appointment-based measures in capturing engagement is that patients may attend appointments consistently to access benefits, obtain pain medication, or decrease isolation but may not be optimally engaged. There are important factors of engagement that are not encapsulated by existing definitions and without a thorough understanding of these factors, efforts to create effective tailored interventions will be lacking. Therefore, the objective of our study was to identify and develop a composite of engagement in HIV care (CEHC) among HIV-positive individuals to better delineate the elements of engagement in care.

Methods

Study Design

We conducted a cross-sectional study using an online survey among HIV-positive individuals recruited through online social media to identify a CEHC and examine the correlation between this composite and self-reported virologic undetectability among HIV-positive individuals. The University of California, San Francisco (UCSF) Committee on Human Research approved this study in April 2013.

Recruitment and Study Participants—The methodology for this previously-described study(Yuan, Bare, Johnson, & Saberi, 2014) included implementing a campaign approach where participants were recruited through advertisements on online social media (e.g., Facebook and Twitter) and data were collected using an online survey tool (Qualtrics Research Suite [Qualtrics, Provo, UT]) from May through August 2013. Individuals who clicked on the web link for the study were directed to the survey where they were they were consented online before being screened for eligibility. We included individuals who reported being ≥18 years of age, HIV positive, and currently living in the United States. Our survey programming tool allowed for construction and distribution of online surveys in real-time and was programmed to automatically disqualify duplicate Internet Protocol (IP) addresses.

We did not offer monetary incentives to minimize duplicate and false responses. Instead, we inserted stimulating health facts throughout the survey to keep participants engaged.

Variables

Demographics—These data included participants' age, sex at birth, race/ethnicity (White/Caucasian, Black/African American, Latino/Hispanic, other), sexual orientation (gay/homosexual, heterosexual, other), and perceived financial situation ("I have enough money to live comfortably", "I can barely get by on the money I have", "I cannot get by on the money I have").

HIV clinical outcomes—Participants were asked whether their last HIV viral load test was detectable or undetectable. This assessment approach has been validated with laboratory HIV viral load assay results(Kalichman, Rompa, & Cage, 2000). Participants' ARV adherence over the past 30 days was assessed using a 30-day visual analog scale (VAS) (Oyugi et al., 2004) and a validated adherence rating scale(Lu et al., 2008) which categorizes adherence as "excellent", "very good", "good", "fair", "poor", and "very poor". This single item has been linked to more objective ARV adherence estimates, such as medication event monitoring systems (MEMS)(Lu et al., 2008). The approximate correlation of the VAS and the rating scales is as follows: very poor= 0%, poor= 20%, fair= 40%, good=60%, very good=80%, and excellent=100%.

Engagement in care was assessed by the following self-reported variables: 1) having attended an appointment with an HIV healthcare provider in the past six months (yes/no), 2) reporting a scheduled future HIV healthcare provider appointment (yes/no), 3) participants knowing their last CD_4^+ cell count (yes/no), 4) knowing their ARV medication names (yes/no), 5) reporting ARV adherence ≥80% on the VAS and "very good" or "excellent" adherence on the rating scale (yes/no), 6) reporting adherence ≥90% on the VAS and "excellent" adherence on the rating scale (yes/no), and 7) not having missed all ARVs for at least four days in a row in the past three months (yes/no). These items were selected *a priori* based on variables that could be assessed by self-report and could potentially encapsulate various components of the HIV Care Continuum(Gardner, McLees, Steiner, Del Rio, & Burman, 2011) and commonly used adherence cut-offs(Ghidei et al., 2013; Mathes, Pieper, Antoine, & Eikermann, 2013; Mills et al., 2006). To create the CEHC, the presence or absence of these variables were summed (range=0–7) and categorized (7="high engagement", 5–6="moderate engagement", and 0–4="low engagement"). Missing data on any variable was set to zero. Therefore, a participant who had reported attending an appointment in the past six month (1 point), not having a future appointment (0 points), knowing his/her CD_4^+ cell count (1 point) and ARV names (1 point), reporting "excellent" adherence on the adherence rating scale and adherence ≥90% on the VAS (2 points), and having missed all ARVs once for four days in a row in the past three months (0 points), would score a total of 5 points (i.e., moderate engagement).

Analysis

Initially, we described the characteristics of those who reported their viral load and calculated their CEHC. Next, we examined the association between the three categories of

CEHC and virologic undetectability in a bivariate logistic regression model. Finally, we evaluated this logistic regression model while controlling for all demographic variables that had a $p<0.25$ in their association with undetectable viral load and conducted backward elimination until all remaining variables had $p<0.05$(Hosmer & Lemeshow, 2000). All analyses were conducted using Stata, version 13.1 (StataCorp, College Station, TX).

Results

We included data from 1,259 HIV-positive participants who had reported their HIV viral load (Table 1). These individuals had a mean age of 47 years, were mainly male (94.7%), White (72.4%), and homosexual/gay (87.4%). Over 94.5% reported taking ARVs, mean VAS adherence was 95.4% (SD= 12.7%), and 84.8% reported having an undetectable viral load. On average, participants had moderate engagement in their HIV care (Table 2). Approximately 89.0%, 87.5%, and 66.8% of those with high, moderate, and low engagement, respectively, had an undetectable viral load. A total of 235 individuals had missing viral load data and were not included in the main data analysis. Among these individuals, 91.5% had low engagement, 7.7% had moderate engagement, and 0.9% had high engagement to HIV care.

In bivariate analyses, there was a statistically significant association between the CEHC and self-reported virologic undetectability (OR for moderate engagement= 3.48, 95% CI= 2.36–5.17, $p< 0.001$; OR for high engagement= 4.03, 95% CI= 2.70–6.03, $p< 0.001$; versus low engagement, overall $p< 0.0001$). Other demographic variables which were significantly associated with virologic undetectability included higher age and race/ethnicity. Lower perceived financial situation and higher education were marginally associated with virologic undetectability.

In the final multivariable logistic regression model, higher CEHC categories were significantly associated with self-reported virologic undetectability (OR for moderate engagement= 3.25, 95% CI= 2.18–4.83, $p< 0.001$; OR for high engagement= 3.49, 95% CI= 2.31–5.27, $p< 0.001$; versus low engagement, overall $p< 0.0001$), after controlling for age and race/ethnicity.

Discussion

The calculation of the CEHC based on appointment attendance in the past 6 months, presence of scheduled future appointment, knowledge of last CD_4^+ cell count and ARV names, adherence ≥80% on VAS and “very good” or “excellent” adherence on rating scale, adherence ≥90% on VAS and “excellent” adherence on rating scale, and not having missed all ARVs for at least 4 days in a row in past 3 months, was associated with higher odds of reporting an undetectable viral load. Even moderate engagement in care (i.e., presence of 5–6 of the 7 factors) was associated with higher odds of reporting an undetectable viral load compared to low engagement in care.

Our study has several limitations. We conducted a cross-sectional study with which causality cannot be established and results may be confounded by unmeasured variables. Our results may not be generalizable to the entire HIV-positive population living in the U.S.,

especially to demographics that were less well-represented in our sample. However, an advantage of Internet-based surveys is the ability to access wide geographic regions and potentially gather data on hidden populations who may be concerned about revealing their identities(Marcus, Schmidt, Hamouda, & Bochow, 2009). We had missing viral load data on 15.7% of our initial study sample and therefore excluded data from these individuals in our main analysis. This pattern of missingness was more pronounced in the low engagement to care group and their exclusion likely biases our results toward the null. Therefore, our point estimates are likely an underestimation of the true association between engagement in care and viral load. We may have had some duplicate or false responses; however, by not providing monetary incentives and automatically disqualifying duplicate IP addresses we believe that this problem had low likelihood of occurrence. The Composite was constructed from *a priori* selected variables; however, additional elements of engagement may strengthen its association with HIV treatment outcomes and provide greater granularity across more levels of engagement. Lastly, we relied on self-reported data (including HIV serostatus, ARV adherence, and viral load), which may be affected by social desirability and other reporting biases.

Our CEHC is a first step toward more thoroughly understanding and identifying elements of engagement that are not captured by the current definitions. Given that virologic failure is preceded by ARV non-adherence, this composite is a potential tool that can be used in clinical practice to identify patients with low engagement and a potentially higher risk of virologic failure in order to provide direction for how to engage them. Future studies should more objectively assess these and other engagement-related components and examine the impact of tailored interventions aimed at improving these factors on HIV treatment goals.

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Table 1

Sample Characteristics

Characteristic		**N= 1,259**	**OR[a] (95% CI)**	**P-value**
Mean age, years (SD)		46.5 (10.9)	1.03 (1.02–1.05)	<0.001
Male at birth, N (%)		1,189 (94.7)	1.56 (0.70–3.46)	0.28
Race, N (%)[b]			-	0.01[c]
	White	911 (72.4)	Reference	-
	Latino	152 (12.1)	1.45 (0.84–2.52)	0.18
	African-American/Black	109 (8.7)	0.52 (0.32–0.83)	0.007
	Other[d]	87 (6.9)	0.82 (0.46–1.47)	0.51
Sexual orientation, N (%)[e]			-	0.30[c]
	Homosexual/gay	1,093 (87.4)	Reference	-
	Heterosexual	85 (6.8)	1.33 (0.68–2.63)	0.41
	Other[f]	73 (5.8)	0.69 (0.38–1.24)	0.21
Perceived financial situation, N (%)[g]			-	0.09[c]
	Live comfortably	480 (39.4)	Reference	-
	Can barely get by	569 (46.7)	0.70 (0.49–0.98)	0.04
	Cannot get by	170 (14.0)	0.67 (0.41–1.08)	0.10
Education, N (%)[h]			-	0.08[c]
	High school degree or less	369 (29.5)	Reference	-
	Any college degree	645 (51.6)	1.27 (0.90–1.79)	0.17
	Higher than college degree	235 (18.8)	1.71 (1.06–2.76)	0.03

SD: standard deviation

[a] Odds ratio (OR) and 95% confidence interval (CI) for undetectable versus detectable viral load

[b] N= 1,256

[c] Omnibus Wald test

[d] Other race includes American Indian, Alaska Native, Asian, Native Hawaiian or other Pacific Islander, Asian American, Pacific Islander, multiracial or multicultural, or other specified race

[e] N= 1,251

[f] Other sexual orientation includes bisexual or not sure

[g] N= 1,219

[h] N= 1,249

Table 2

Composite of Engagement in HIV Care

1- Attended HCP appointment in past 6 months, N (%)[a]		1,175 (93.7)
2- Have scheduled future HCP appointment, N (%)[b]		1,086 (86.6)
3- Knows last CD_4^+ cell count, N (%)[c]		986 (80.1)
4- Knows names of ARVs, N (%)		1,247 (99.0)
5- ARV adherence rating in past 30 days, N (%)[d]		
	Excellent	794 (66.8)
	Very good	264 (22.2)
	Good	62 (5.2)
	Fair	44 (3.7)
	Poor	13 (1.1)
	Very poor	11 (0.9)
6- Visual analog scale categories in past 30 days, N (%)[e]		
	≥90%	1,078 (91.5)
	80–89.9%	41 (3.5)
	<80%	59 (5.0)
7- Has not missed all ARVs for ≥4 days in a row in past 3 months, N (%)[f]		1,025 (86.2)
Composite of Engagement in HIV Care, N (%)[g]		
	High	520 (41.3)
	Moderate	537 (42.7)
	Low	202 (16.0)

ARV: antiretroviral; HCP: healthcare provider

[a] N= 1,254 /

[b] N= 1,250 /

[c] N= 1,231 /

[d] N= 1,188 /

[e] N= 1,178 /

[f] N= 1,189

[g] Composite of Engagement in HIV Care= 1 + 2 + 3 + 4 + 5 + 6 + 7