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Authors

Tran, Nathan
Nishi, Akihiro
Young, Lindsay E
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The role of perceived health in retention disparity: A HIV-testing-related behavioral intervention among African American and Latinx men who have sex with men in the United States

Nathan Tran^a, Akihiro Nishi^{a,*}, Lindsay E. Young^b, Akira Endo^{c,d}, William G. Cumberland^e, Sean D. Young^{f,g,*}

^a Department of Epidemiology, University of California, Los Angeles, Los Angeles, CA 90095, USA

^b Annenberg School for Communication and Journalism, University of Southern California, Los Angeles, CA 90089, USA

^c Department of Infectious Disease Epidemiology, London School of Hygiene & Tropical Medicine, London WC1E 7HT, United Kingdom

^d School of Tropical Medicine and Global Health, Nagasaki University, Nagasaki 852-8523, Japan

^e Department of Biostatistics, University of California, Los Angeles, Los Angeles, CA 90095, USA

^f Department of Emergency Medicine, University of California, Irvine, Irvine, CA 92617, USA

^g Department of Informatics, University of California, Irvine, Irvine, CA 92617, USA

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ABSTRACT

Retention in healthcare and health behavior remains a critical issue, contributing to inequitable distribution of intervention benefits. In diseases such as HIV, where half of the new infections occur among racial and sexual minorities, it is important that interventions do not enlarge pre-existing health disparities. To effectively combat this public health issue, it is crucial that we quantify the magnitude of racial/ethnic disparity in retention. Further, there is a need to identify mediating factors to this relationship to inform equitable intervention design. In the present study, we assess the racial/ethnic disparity in retention in a peer-led online behavioral intervention to increase HIV self-testing behavior and identify explanatory factors. The research used data collected from the Harnessing Online Peer Education (HOPE) HIV Study that included 899 primarily African American and Latinx men who have sex with men (MSM) in the United States. Results show that African American participants had higher lost-to-follow-up rates at 12-week follow-up compared to Latinx participants (11.1% and 5.8% respectively, Odds Ratio = 2.18, 95% confidence interval: 1.12 – 4.11, $p = 0.02$), which is substantially mediated by participants' self-rated health score (14.1% of the variation in the African American v.s. Latinx difference in lost-follow-up, $p = 0.006$). Thus, how MSM perceive their health may play an important role in their retention in HIV-related behavioral intervention programs and its racial/ethnic disparity.

1. Introduction

Maintaining retention in healthcare and behavioral programs remains an important challenge in medicine. (Bauermeister et al., 2021; Coday et al., 2005) A systematic review has shown that 22.5% of participants who had been interested in and agreed to participate in health-related behavioral interventions were lost to follow-up before these interventions ended. (Trivedi et al., 2013) High loss to follow-up in intervention programs poses challenges to accurate conclusions. (Modern, 2021) For example, compromised retention obscures the internal validity by skewing the effect size of the treatment or intervention

programs, especially when loss-to-follow-up occurs non-randomly. (Hernan and Robins, 2023) In addition, higher loss to follow-up rates among racial/ethnic minority groups, which have been reported consistently across various domains including HIV, (Anderson et al., 2021) could exacerbate health disparities between minority and other groups at the end of the intervention programs.

In theory, perception of health status (which can be measured by a single-item self-rated health question) (Sen, 2002) should play a vital role in participants' retention in intervention programs and in racial/ethnic disparities in behavioral retention. Because social, cultural, and educational backgrounds can shape perception and interpretation of

* Corresponding authors at: Department of Epidemiology, Fielding School of Public Health, 650 Charles E Young Dr S, Los Angeles, CA 90095 (A. Nishi); Department of Emergency Medicine, University of California, Irvine, 6091 Bren Hall, CA 92617 (S.D. Young).

E-mail addresses: akihironishi@ucla.edu (A. Nishi), syoung5@hs.uci.edu (S.D. Young).

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patient health conditions and symptoms, (Jylhä, 2009) substantial variation in the distribution of the self-rated health measure over different racial/ethnic groups is anticipated. Moreover, one’s perception of health status may determine the subjective value of healthcare and health-related intervention programs. If a patient does not have remarkable symptoms or believes they are healthy, the opportunity cost to seek healthcare or participate in an intervention program may outweigh the potential benefit from pursuing healthcare or continuing program participation. (Zeng et al., 2021).

Despite this hypothesis, past literature shows that the relationship between race/ethnicity, self-rated health, and retention has not yet been well established. Regarding the connection between race/ethnicity and self-rated health, one study used the National Health and Nutrition Examination Survey (NHANES) and shows that Latinx participants are 1.45 times more likely than African American participants to self-report their health as poor or fair potentially because of low education level, poor primary care experience, limited access to healthcare, or other reasons, (Gandhi et al., 2020) while another study shows there was only negligible difference in self-rated health between African American and Latinx populations. (Shippee et al., 2020) Regarding the connection between self-rated health and retention in behavioral interventions, one study aiming to increase physical wellness behaviors found that good perceived health increases retention, (Martinez et al., 2006) while another study aiming to increase exercise behaviors found no relationship between perceived health and retention. (Schmidt et al., 2000) Although the connection between race/ethnicity and self-rated health and retention in behavioral interventions have been explored separately, each with unclear results, there are no studies that have linked self-rated health as explanatory of racial/ethnic retention disparities.

The area of retention is of particular interest to the HIV care continuum, which is composed of five stages: disease acquisition, diagnosis, assessment, initiation of treatment, continuation of treatment, and discharge or death. (Stricker, 2014) According to a review article, Black participants are less likely to be retained across all five stages of the HIV care continuum than both Non-Hispanic White and Hispanic participants. (Anderson, et al., 2020) In relation to men who have sex with men

(MSM), self-rated health is most often studied as an outcome variable, in which researchers identify the determinants of self-rated health among MSM. For example, while one study consisting of a Canadian community-sample found that loneliness mediates differences in self-rated health among MSM, (Marziali et al., 2020) another study consisting of a sample of Australian MSM living with HIV found that employment status, recent sexual activity, social support, and socio-economic status mediate differences in self-rated health. (Koelmeyer, Jan. 2014) While retention has been well studied across the HIV care continuum, there are no studies to date that have examined retention disparities in HIV-testing-specific interventions.

In this study, we focus on African American and Latinx men who have sex with men (MSM), who accounted for 50% of newly diagnosed HIV cases in the US in 2019. (HIV Incidence et al., 2022) We aimed to quantify the magnitude of racial/ethnic difference in retention and identify key components that can address a potentially higher loss to follow-up in different race/ethnic minority groups including self-rated health (see our conceptual model at Fig. 1A).

2. Methods

2.1. Data

The Harnessing Online Peer Education (HOPE) HIV Study (UCLA IRB #14-001923) was an individually randomized group-treatment trial (IRGT), which aimed to test the efficacy of a 12-week peer-led Facebook-based intervention on HIV self-testing behavior. (Young et al., 2022) The details of the trial are available elsewhere but briefly, (Young et al., 2022) study participants were men who were 18 years or older, living in the greater Los Angeles area, having had sexual intercourse with another man in the last 12 months, and HIV negative and/or HIV serostatus (N = 900 in six waves between 2016 and 2020). This study was comprised primarily of African American and Latinx MSM in the greater Los Angeles area. In our analysis, we omitted one study participant due to his duplicate participation (the resulting N = 899). Trained peer leaders, who were mostly African American or Latinx, were instructed to facilitate both community building activities and discussions surrounding

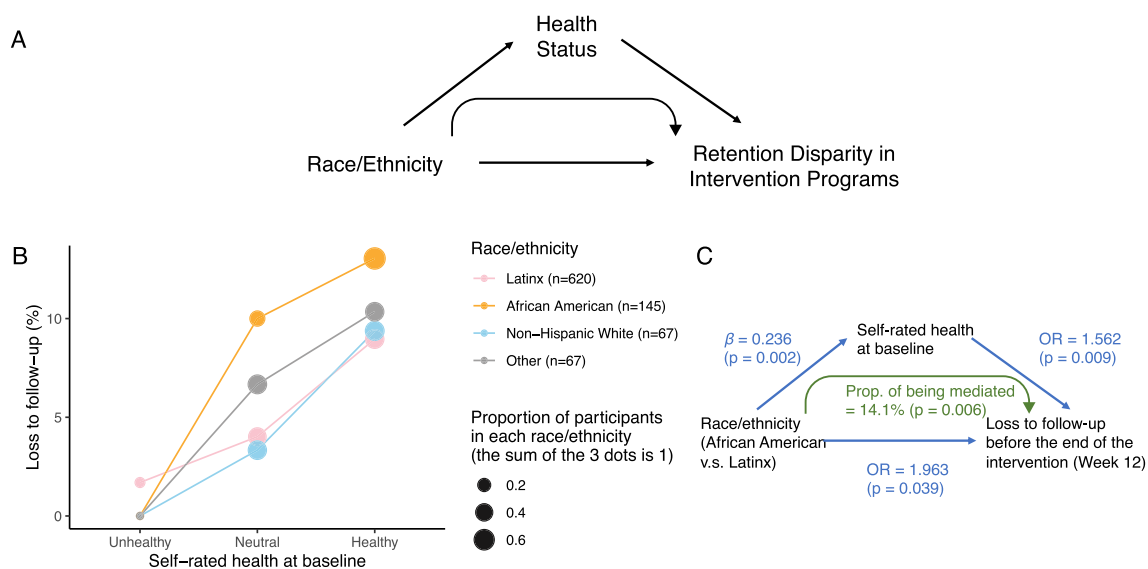


Fig. 1. A. Conceptual framework: health status mediates racial/ethnic retention disparities in intervention programs. Direct paths exist between race/ethnicity and health status, health status and retention disparities in intervention programs, and race/ethnicity and retention disparity in intervention programs. An indirect path also exists where health status mediates retention disparity in different racial/ethnic groups. **B. The loss to follow-up rate over different racial/ethnic groups with different self-rated health at baseline.** The two categories (very unhealthy and unhealthy) were merged as “unhealthy”, and the other two categories (healthy and very healthy) were also merged as “healthy.” Circle sizes represent the proportions of participants in each racial/ethnic category. **C. Mediation analysis.** An indirect path from race/ethnicity to loss to follow-up through self-rated health was examined simultaneously with a direct path from race/ethnicity to loss to follow-up.

HIV testing and HIV prevention.

Study participants were then randomly assigned within waves to either an intervention group or a control group (30 participants per group, 15 intervention groups and 15 control groups over 6 waves). Participants in both conditions were informed to use Facebook groups as they would normally, with no obligation to participate or stay involved in the group. They were not compensated for their participation in the group (only for completing surveys) and were not instructed to discuss or not discuss any topics. Informed consent was conducted through an online written information sheet. Peer leaders were randomly assigned to the intervention groups; their roles were to lead community building and HIV education efforts within the Facebook group. Each study participant in the intervention group was also paired with at least 2 peer leaders for individual questions and concerns. There were no peer leaders placed in the control groups. During the 12-week active intervention period, study participants were offered HIV testing kits every 4 weeks for the 12-week period.

In our previous paper, (Young et al., 2022) we reported that participants in the intervention groups were more likely to accept the HIV self-testing kit offer (29.0% for intervention versus 22.7% for control; odds ratio = 1.43, 95% confidence interval: 1.04 – 1.95). A total of 29 participants and 32 participants were lost to 12-week follow-up in the intervention groups and control groups respectively, (Young et al., 2022) which was comparable to our previous study of a different series of interventions in 2014; (Young, 2014) however, the sociodemographic determinants of the loss to follow-up rates were not reported or examined.

2.2. Measures

The baseline survey includes the measures of age (years), self-reported race and ethnicity, educational attainment, the baseline social media use (hours of social media use per week), the number of sexual partners in the past three months, and self-rated health.

Self-rated health is one of the most widely adopted health-status measures around the world due to its brevity, reliability and validity. (Bowling, 2005; Dowd and Zajacova, 2010) We assessed self-rated health using the question, “please rank your perceived health?” Six answer options were provided: very unhealthy, unhealthy, average, healthy, very healthy, and don’t know. The first five options were converted to a discrete variable ranging from –2 to 2.

2.3. Statistical analysis

All data analysis was performed in R version 4.1.3 (Foundation for Statistical Computing, Vienna, Austria). Since the study was designed to primarily recruit MSM of color, the majority of the participants were Latinx (n = 620, 69.0%), which was used as a reference group.

First, we developed a model to explain the dichotomous outcome variable representing loss to follow-up at week-12. We used R lme4 package (Bates et al., 2015) to employ a multilevel analysis, where we accounted for the two layers of the hierarchical data structure: the group assignment and the waves, in addition to controlling for covariates (age and intervention/control). We used the R “lmerTest” package (Kuznetsova et al., 2017) and calculated p values with the Satterthwaite approximation (please note that the results did not substantially change when we used simpler models such as a logistic regression model).

Second, we also used the R “mediation” package (Tingley et al., 2014) to perform mediation analysis, which could quantify separately an indirect effect (via an intermediate factor) and a direct effect (not via an intermediate factor) for identifying factors that could explain the association between race/ethnicity and loss to follow-up rate. Since the current method does not support two levels of clusters, we used groups as a specified level of cluster (please note that the results did not substantially change when we used waves as a specified cluster). Here, we explored the role of self-rated health (converted to a discrete variable

ranging from –2 to 2 for analysis) as well as educational attainment, social media use, and the number of sexual partners in the past three months as potential mediators to explain racial and ethnic differences in the outcome variable representing loss to follow-up at week-12.

3. Results

We found that African American participants were more likely to be lost to follow-up at week-12 than Latinx participants (11.1% and 5.8% respectively, Odds Ratio [OR] = 2.18, 95% confidence interval (CI): 1.12 – 4.11, p = 0.02) (Table 1). The loss to follow-up rates among Non-Hispanic White (6.0%) and other participants (7.5%) did not deviate from that of Latinx participants (p = 0.67 and p = 0.56 respectively). Better self-rated health was associated with a higher loss to follow-up across all the race/ethnic groups (OR = 1.71, 95% CI: 1.20 – 2.42, p = 0.003) (Fig. 1B). Mediation analysis revealed that self-rated health

Table 1
Socio-demographic characteristics, self-rated health, and the week-12 retention at the HOPE HIV Study.

		Latinx (%)	African American (%)	Non-Hispanic White (%)	Other (%)
N (total, 899)		620	145	67	67
Wave	1	113 (18.2)	37 (25.5)	12 (17.9)	18 (26.9)
	2	79 (12.7)	19 (13.1)	13 (19.4)	9 (13.4)
	3	67 (10.8)	28 (19.3)	14 (20.9)	11 (16.4)
	4	136 (21.9)	19 (13.1)	12 (17.9)	13 (19.4)
	5	96 (15.5)	15 (10.3)	5 (7.5)	4 (6.0)
	6	129 (20.8)	27 (18.6)	11 (16.4)	12 (17.9)
Treatment	Control	319 (51.5)	73 (50.3)	28 (41.8)	29 (43.3)
	Intervention	301 (48.5)	72 (49.7)	39 (58.2)	38 (56.7)
Age, mean (SD)		30.1 (8.34)	34.7 (10.45)	35.1 (13.09)	31.6 (8.35)
Education	High School or Less	203 (32.7)	36 (24.8)	16 (23.9)	19 (28.4)
	Associate Degree	121 (19.5)	24 (16.6)	10 (14.9)	15 (22.4)
	Bachelor’s Degree	203 (32.7)	60 (41.4)	27 (40.3)	18 (26.9)
	Graduate Degree	93 (15.0)	25 (17.2)	14 (20.9)	15 (22.4)
	Self-rated health	Very Unhealthy, –2	5 (0.9)	1 (0.7)	0 (0.0)
	Unhealthy, –1	54 (9.2)	6 (4.3)	2 (3.1)	2 (3.2)
	Average, 0	249 (42.4)	40 (28.8)	30 (46.9)	30 (48.4)
	Healthy, 1	218 (37.1)	70 (50.4)	26 (40.6)	25 (40.3)
	Very Healthy, 2	61 (10.4)	22 (15.8)	6 (9.4)	4 (6.5)
The week-12 loss to follow-up rate	Lost to follow-up	36 (5.8)	16 (11.0)	4 (6.0)	5 (7.5)
	Retained	584 (94.2)	129 (89.0)	63 (94.0)	62 (92.5)

explains greater loss to follow-up among African American participants compared to Latinx participants by 14.1% ($p = 0.006$) (Fig. 1C) but not by educational attainment ($p = 0.14$), social media use ($p = 0.33$), or the number of sexual partners in the past three months ($p = 0.26$).

4. Discussion

To our knowledge, this is the first study that suggests the role of self-rated health in racial/ethnic disparities in behavioral intervention programs encouraging HIV testing. As such, self-rated health can be monitored in behavioral interventions at a low cost to identify study participants who are more likely to be lost-to-follow-up. This finding can also be translated to the bedside, where physicians can monitor self-rated health to identify patients for counseling in HIV self-testing. This is clinically relevant to HIV due to its long clinical latency period: (Siliciano and Greene, Sept. 2011) better and worse self-rated health does not indicate the negative or positive status of HIV infection. Thus, those with good self-rated health may still find benefit from HIV-related knowledge provided by the HIV HOPE Study and other sources. Our results regarding the mediation by self-rated health may explain the results in past studies showing that African American MSM were self-tested less frequently and were less likely to be aware of their HIV status. (Millett et al., 2006) Moreover, while our study examines the role of self-rated health in the race/ethnicity-retention axis in MSM populations and HIV-testing behavior, our findings may be pertinent to other populations and behaviors, where we expect self-rated health to also mediate racial/ethnic retention disparities.

Limitations include that the HOPE HIV study has achieved very low loss to follow-up rates overall, which might reduce potential differences that we could find. While this aspect may be considered a limitation in the context of our study, it may be of interest for future intervention researchers who aim to achieve similar retention rates. We attribute our high retention rates to our social media communities, which keep people engaged, and to our research staffs' work in following up with participants. (Young, 2014).

Because racial/ethnic minorities are less likely to be retained in every step of the HIV care continuum, it is imperative that interventions be iterative and adaptive to new findings that identify causes for inequities. While our intervention focused on preventive aspects of HIV and positioned community leaders to expand knowledge on HIV self-testing, the benefits of our study were attenuated by racial/ethnic disparities in retention. Our novel finding that self-rated health partially mediated this relationship informs future behavioral interventions that aim to equitably promote health within and outside of both HIV contexts and MSM populations. We suggest that future studies validate the reproducibility of our findings outside of this single trial.

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The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: AN is a consultant to Vacan, Inc. AE received a research funding from Taisho Pharmaceutical Co., Ltd. SDY has received gift funding as PI from Facebook to the University of California and is an advisor to ElevateU and other digital health startups.

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Data availability

The data that has been used is confidential.

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