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Quality of Life in People With HIV at the End of Life: Preliminary Results From the Last Gift Observational Cohort Study

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Background: As people living with HIV (PWH) age, they face new challenges that can have a negative impact on their quality of life (QOL) and mental health.

Setting: This study enrolled PWH at the end of life (EOL) who were actively engaged in cure-related research in Southern California, United States. EOL was defined as having a prognosis of 6 months or less to live. We examined the relationship between QOL, mental health, and research participation.

Methods: Structured assessments were used to collect comprehensive data on QOL and mental health.

Results: From 2017 to 2023, 35 PWH in their final stages of life who were actively engaged in cure-related research were enrolled. Their median age was 62.7 years, and most were White or otherwise non-Hispanic/non-Latino (90.6%), and male (86.7%). Changes in QOL and the presence of neurologic and psychiatric conditions, with a focus on depression and anxiety, were the primary outcomes assessed in this study. Participants had stable QOL scores throughout the study. There was an inverse relationship between QOL and Beck Depression Inventory scores, with higher mean QOL scores being associated with lower mean Beck Depression Inventory scores ($P < 0.001$).

Conclusions: QOL remained stable among PWH who participate in cure-related research at EOL. The inverse relationship between QOL and depressive symptoms suggests that participation in cure-related research may improve QOL or reduce depressive symptoms in this population. Future interventions should look into ways to improve the well-being of PWH at EOL through research and customized mental health interventions.

Key Words: quality of life, people with HIV, end of life, Last Gift, mental health, depression, anxiety

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INTRODUCTION

Improved efficacy of antiretroviral therapy has substantially increased the average life expectancy for people with HIV (PWH).[1] An evolving field of HIV research has

focused on improving quality of life (QOL), which is an individual's health status as influenced by social, psychological, physical, and functional well-being.[2–4] PWH often experience challenges that may affect QOL or worsen mental health, including stigma, physical and mental health comorbidities, utilization of antiretroviral therapy, medication side effects, lower socioeconomic status, and loss of social support systems.[5–10]

As the population of PWH ages, it is becoming increasingly important to monitor and improve QOL and mental health. Older PWH have been shown to be less satisfied with their social support networks, more frequently engage with unhealthy coping mechanisms, and experience a more substantial decline in QOL over time when compared with younger PWH.[7,11] Sparse data exist on how a person's QOL changes with the progression of disease morbidity, especially at end of life (EOL). One study found that people living with advanced cancer often experienced relatively stable QOL until the last few months of life, whereupon QOL decreased significantly.[12] Other studies identified gradual decreases in QOL at EOL among older people living with Parkinson or Alzheimer diseases.[13,14] Data regarding the predictors of QOL specifically at the EOL for PWH, however, remain limited.

Improving health and support services at the EOL improves QOL and has led to broad implementation of hospice and palliative care services; however, alternative and more accessible methods to improve QOL at EOL are limited.[15] We previously identified that participants in the Last Gift tissue donation study at the University of California San Diego (UCSD) reported high levels of satisfaction from their participation that otherwise offered no potential health benefits.[16] The UCSD Last Gift is an observational study that enrolls PWH with a prognosis of 6 months or less to live (eg, hospice-qualifying condition) who provide blood (and occasionally other bodily fluid) samples. Since 2017, the study has enrolled approximately 5 PWH per year into EOL HIV cure-related research. Enrolling PWH near the EOL allows a rapid research autopsy to enable researchers to characterize HIV reservoirs throughout the body.[16–18] Last Gift participants can also choose to engage in sociobehavioral interview assessments to evaluate their QOL and mental health. We hypothesized that QOL and mental health are inversely correlated at the EOL and that Last Gift participants would exhibit relatively stable QOL and mental health, because of HIV-specific altruism from involvement in cure-related research at EOL.

METHODS

Study Participants and Setting

The UCSD Last Gift study enrolls PWH at the EOL. Participants are recruited through referrals from HIV clinics in Southern California, such as the UCSD Owen Clinic and the Veterans Affairs Hospital of San Diego. Terminal illnesses have included various cancers and end-stage organ diseases and neurodegenerative illnesses.

Data Collection

From 2017 to 2023, Last Gift team members conducted baseline and follow-up interviews with participants. The baseline interview reviewed demographic characteristics (eg, age at enrollment, sex assigned at birth, gender, race, ethnicity, sexual orientation, education, current homelessness), medical history (verified with electronic medical records), and assessed QOL at EOL,[19,20] mental health, and substance use using standard self-reported measures. Participants underwent follow-up interviews at periodic intervals (approximately every 1–3 months), depending on their prognosis and their time on the study. Research staff (S.S., C.D., S.C.-G.) administered surveys in person and entered survey responses directly into the UCSD Last Gift RedCap database (Vanderbilt University, TN). Participants received $20 compensation for baseline interviews, and $10 for follow-up interviews.

QOL at the EOL

We used the Quality of Life of Seriously Ill Patients to assess QOL at the EOL.[19,20] The assessment included 26 items that are associated with 5 factors (ie, Life Completion, Relationship with Healthcare Provider, Preparation for End of Life, Symptom Impact, and Affective Social Support). All items were scored on a 5-point Likert scale. Items for the Symptom Impact and Preparation for EOL factors were reverse scored to ensure that higher scores indicated better QOL. The submitted scores for each item in the assessment were then averaged to determine a mean score by RedCap event (baseline, follow-up 1, follow-up 2, etc).

Beck Depression Inventory

We administered the Beck Depression Inventory (BDI) with permission for use, which included a 21-item self-report questionnaire.[21] All items are scored on a 0–3-point scale of severity, with the total score ranging from 0 to 63 and a higher score predicting greater depressive symptoms (eg, scores of 17–20 indicate borderline clinical depression, 21–30 indicate moderate depression, 31–40 indicate severe depression, and 41+ indicate extreme depression).

Substance Use

During the baseline interview, we asked participants to indicate whether they had ever used the following substances: alcohol, anxiolytic medications, cocaine (crack), dissociative substances, ecstasy, hallucinogens, heroin, inhalants, marijuana (injected, smoked, vaporized, other), methamphetamine, nicotine (vaporized), others (ie, opioids, stimulants), poppers, sedatives, and tobacco (smoked, other). At follow-up visits, participants were asked whether they had used any of the aforementioned substances during the recent interval of time between their current and previous evaluation.

Data Analyses

Descriptive analyses were used to summarize the data. For QOL and BDI at the EOL, we report median (median absolute deviation). We also report the number of participants with probable depression diagnosis based on any BDI score ≥14. For substance use questions, and medical history, we report proportions and frequencies.

Linear mixed-effects regression was used to assess the association between primary outcomes of mean QOL score or BDI score and predictors of interest. Bivariate models were estimated to assess the marginal effect of elapsed time since baseline evaluation on the primary outcomes. For the QOL outcome, a subsequent model was fit to estimate the effect of BDI score while controlling for duration of follow-up in the study. Sensitivity to participants with longer follow-up was assessed by refitting these models restricted to data in the first year of follow-up. Models were fit to estimate the association between primary outcomes and indicators for neurologic or psychiatric disorders, and indicators for recent substance use. Separate models were also fit for each disorder and substance and included duration of follow-up in the study as a covariate. All mixed models included a random intercept by participant. *P*-values were corrected for multiple comparisons using the Holm method. Analyses were completed using the Statistical Software R version 4.3.0 (Indianapolis, IN). Survival status refers to whether, at the time of the analysis, participants were still alive.

Ethical Considerations

The UCSD IRB approved the Last Gift study (Project #160563) with the QOL and sociobehavioral research component. All participants provided written informed consent to be interviewed. Participants with high BDI scores who did not actively see a mental health provider were referred for evaluation through their medical provider and given a mental health services list. If suicidal ideation was indicated on the BDI or verbalized during the interview, the clinical psychologist at the HIV Neurobehavioral Research Center was consulted.

RESULTS

Last Gift Participants

The 35 participants included in this analysis were predominantly older (median age 62.7 years), White or otherwise non-Hispanic/non-Latino (90.6%, N = 29), and male (86.7%, N = 26) (Table 1). Furthermore, 61.1% (N = 11) reported a bachelor's and/or advanced degree, and 10.0% (N = 3) were experiencing housing instability. All participants completed the baseline interview and contributed either or both the QOL and BDI assessments; 24 completed the first follow-up interview. As participants passed away, the number of follow-up interviews declined. Only 7 participants remained in the study by the 7th follow-up interview and only 2 were participating in the study by the 12th interview. Ten participants had more than 1 year of follow-up, with 7 having QOL and 6 having BDI assessments beyond 1 year. Figure S1, Supplemental Digital Content, http://links.lww.com/QAI/C370 provides the timeline of visits relative to baseline for each participant.

QOL at the EOL

A total of 96 QOL assessments were collected from 19 participants. Each participant contributed 1–9 assessments with a median of 6 per participant (Fig. 1). We found that mean QOL scores were high on average (ie, a score of 4 out of 5) and did not statistically change over the course of the study (*P* = 0.243; model M1 in Table 2), although there was a slight increase in mean QOL scores with time. Seven participants had QOL assessments beyond 1 year of follow-up. A subsequent model restricted to the first year of follow-up was fit to assess potential confounding related to longer follow-up. It further indicated that there was no significant change in mean QOL scores over the course of serial assessments (*P* = 0.674).

Mental Health Through BDI at the EOL

A total of 90 BDI assessments were collected from 21 participants. Each participant contributed between 1 and 10 assessments with a median of 5 assessments per participant (Fig. 1). Mean BDI scores remained stable over the course of the study (*P* = 0.590; model M2 in Table 2), although there was a slight increase in mean BDI scores over time. Six participants had BDI assessments beyond 1 year of follow-up. A subsequent model restricted to data in the first year of follow-up was fit to assess potential confounding related to longer follow-up. The model further indicated that mean BDI scores remained stable over the course of serial assessments (*P* = 0.608) (Fig. 2).

Figure S2, Supplemental Digital Content, http://links.lww.com/QAI/C370 provides the prevalence of neurologic or psychiatric conditions from completed baseline medical history. Table S1, Supplemental Digital Content, http://links.lww.com/QAI/C370 provides the summary for QOL and BDI outcomes.

Substance Use at the EOL

At baseline, 1 participant reported recent use of cocaine/crack (Fig. 3). Two participants reported recent use of methamphetamine, with 1 participant reporting use in 4 intervals between evaluations. One participant indicated recent use of hallucinogens. Five participants indicated recent use of antianxiety medications, with 4 indicating consistent use of these agents across 3–7 consecutive intervals between evaluations while enrolled in the study.

DISCUSSION

Our findings demonstrate a statistically significant inverse correlation between QOL and depression among PWH at EOL, confirming our hypothesis that PWH with less depressive symptoms are more likely to report higher QOL. This finding corroborates conclusions from other studies of PWH that indicate that more severe depressive symptoms correlate with lower QOL.[22–28] To our knowledge, this is the first study to demonstrate this association among PWH at EOL.

An inverse relationship between depressive symptoms and QOL has important implications for monitoring and evaluating QOL among PWH at EOL, particularly for PWH who live with depression or who have a history of depression. PWH experience disproportionate rates of

TABLE 1. Demographic and Clinical Characteristics for all Participants (N = 35)

Characteristic	Level	N (%) or Median (Interquartile Range)
Age at enrollment		62.7 (53.4–72.3)
Sex assigned at birth	Female	4 (13.3)
	Male	26 (86.7)
Gender	Female	4 (13.3)
	Male	25 (83.3)
	Does not identify as female, male, or transgender	1 (3.3)
Race	Asian	1 (3.1)
	Black or African American	2 (6.2)
	White/Caucasian	29 (90.6)
Ethnicity	Hispanic/Latino(a)	3 (9.4)
	Not Hispanic/Latino(a)	29 (90.6)
Sexual orientation	Homosexual	12 (48.0)
	Heterosexual	7 (28.0)
	Bisexual	3 (12.0)
	Declined to state	3 (12.0)
Education	High school diploma or general education development	2 (11.1)
	Some college	5 (27.8)
	Bachelor's degree	6 (33.3)
	Advanced degree	5 (27.8)
Active housing instability	Yes	3 (10.0)
	No	27 (90.0)
Last plasma HIV RNA <50 copies/mL	Yes	26 (76.5)
	No	8 (23.5)
Last CD4$^+$ T-cell count (cell/μL)		219.0 (102.5–445.8)
CD4$^+$ T-cell nadir (cell/μL)		86.0 (50.5–245.5)

depression and are at higher risk of developing depressive symptoms compared with people without HIV.[6,29,30] Because lower QOL and a history of psychiatric disorders have been independently associated with higher risk for other HIV-related health outcomes and reduced antiretroviral therapy adherence, our finding of an inverse correlation between QOL and depressive symptoms at the EOL urges routine assessments to optimize long-term management of health and well-being among PWH. Close monitoring and interventions are particularly prudent among PWH who are of older age and/or are at the EOL, because a higher prevalence of accompanying health burdens and risk of diminished cognitive functioning can significantly negatively affect QOL in these populations.[7,31]

Assessments of depression at the EOL may improve treatment plans and/or support programs to address QOL for PWH. Future studies should focus on evaluating how specific variables decrease depressive symptoms to improve QOL at EOL for PWH, ideally facilitating the development of intervention strategies such as health education, palliative care programs, mindfulness, compassion, or stress and anxiety management training. Insofar as QOL and depressive symptoms are inversely correlated at the EOL, health care professionals should emphasize management of depressive symptoms as a potential key intervention to address overall QOL among PWH at the EOL. PWH at the EOL may likely benefit from customized psychological support and further efforts to destigmatize conversations and interventions around behavioral health concerns.

Furthermore, after controlling for mean BDI score, we identified a trend of increasing mean QOL scores over the progression of involvement in the UCSD Last Gift program; however, this finding is not significant when restricted to the first year of follow-up, suggesting that PWH at the EOL perceive a relatively stable, if not slightly improved, QOL in the setting of chronic, terminal illness. The trend is notable in the context of prior analyses, wherein data collected from an earlier stage of the UCSD Last Gift cohort indicated that HIV-specific altruism and the opportunity to leave a legacy through HIV cure research proved to be primary motivators to enroll in the study.[16] At that point in the study, many participants were found to have perceived emotional, psychological, and social benefits from their participation.[16] We did not use a standardized altruism scale in this study. The key impact of social relationships on perceived QOL has also been substantiated through evaluations of QOL among patients who survive a stroke and among patients diagnosed with cancer who receive hospice care, wherein participation in social relationships and/or interventions at the EOL improves self-reporting of QOL.[32,33]

Notably, approximately 35% of Last Gift participants reported a history of depression, closely matching a large meta-analysis that reports that approximately 39% of PWH experience depressive symptoms.[34] Our findings should be contextualized by the COVID-19 pandemic, as the study's serial evaluations of many participants spanned the duration of the most significant phases of the pandemic (2020–2022). Our data demonstrate that mean BDI scores among Last Gift
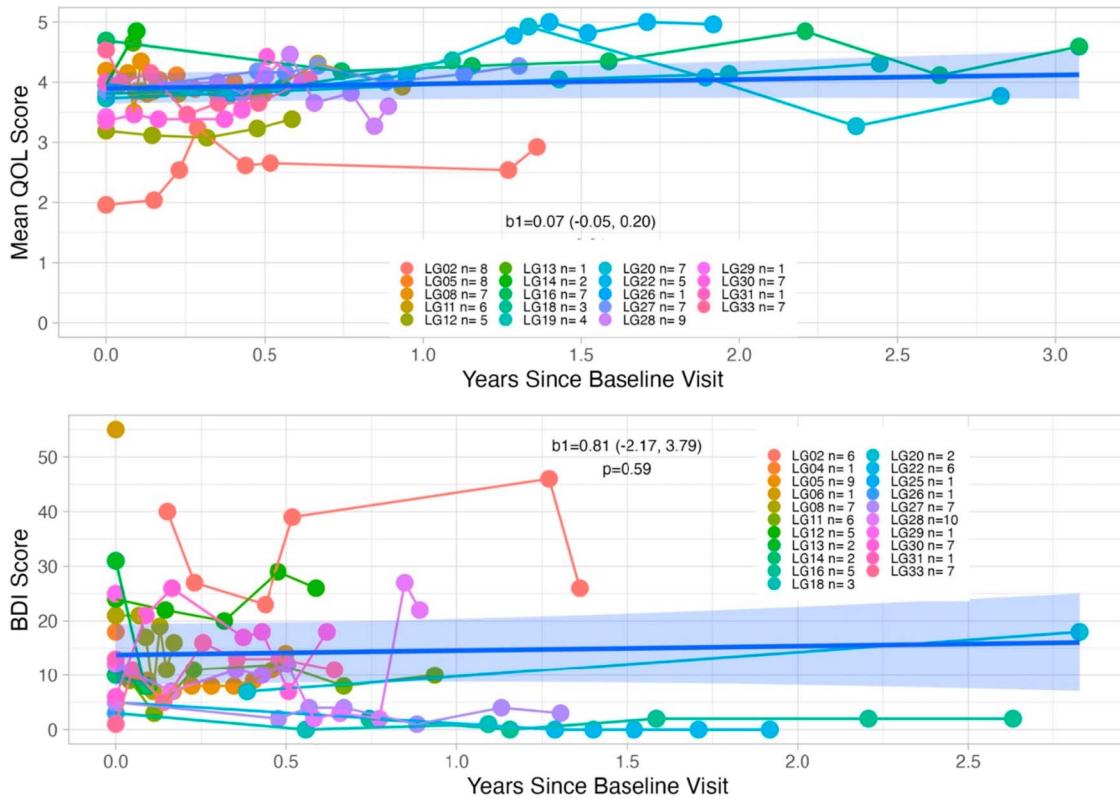
FIGURE 1. Mean QOL and BDI scores over time for each participant (The bold blue lines indicate the expected score estimated by models 1 and 2 in Table 2 along with the estimates, 95% confidence intervals, and *P*-values for the slopes. The legend labels show the total number of QOL or BDI assessments for each participant.).

participants remained stable at the EOL. These findings are consistent with other studies that have shown that, despite a disproportionate rate of exacerbated or new-onset psychological illness among PWH throughout the COVID-19 pandemic, most of PWH did not experience a significant change in their mental health.[35,36] To what extent EOL experiences specifically influence the stability of reported depressive symptoms or changes in QOL remains unclear. Nevertheless, our findings challenge common perceptions of

what patients living with chronic disease or illnesses with a terminal prognosis may experience regarding their QOL or depressive symptoms at the EOL.

Finally, although substance use among older PWH is common, and decreased QOL has been clearly associated with specific forms of substance use, limited data are available to assess the specific impact of different types of substance use on QOL in PWH at the EOL.[11,37–40] This study assessed the potential correlation between various forms of substance use and QOL or depressive symptoms. The use of these substances was reported by few participants; accordingly, correlations regarding the use of specific substances and QOL or BDI scores are underpowered.

TABLE 2. Estimates for Models M1–M3 for the Effect of Time Since Baseline on QOL and BDI Scores (Model M3 is Also Adjusted for BDI Score)

Model	Outcome	Term	Estimate	95% Confidence Interval	P
M1	QOL mean score	Intercept	3.90	3.64 to 4.15	<0.001
		Years since baseline	0.07	−0.05 to 0.20	0.243
M2	BDI score	Intercept	13.77	8.04 to 19.50	<0.001
		Years since baseline	0.81	−2.17 to 3.79	0.590
M3	QOL mean score	Intercept	4.19	3.99 to 4.38	<0.001
		BDI score	−0.03	−0.04 to −0.02	<0.001
		Years since baseline	0.18	0.05 to 0.31	0.008

Limitations

The UCSD Last Gift cohort comprised a relatively small population of individuals from San Diego, California, who live with HIV and have a terminal diagnosis with a prognosis of 6 months or less. Although this presents a unique and key population, the study was limited by the small recruitment pool of individuals; accordingly, we primarily report descriptive rather than inferential results. Data were collected from a total of 35 participants, limiting the comparability or generalizability of our results with the general population of PWH or the larger American public. All
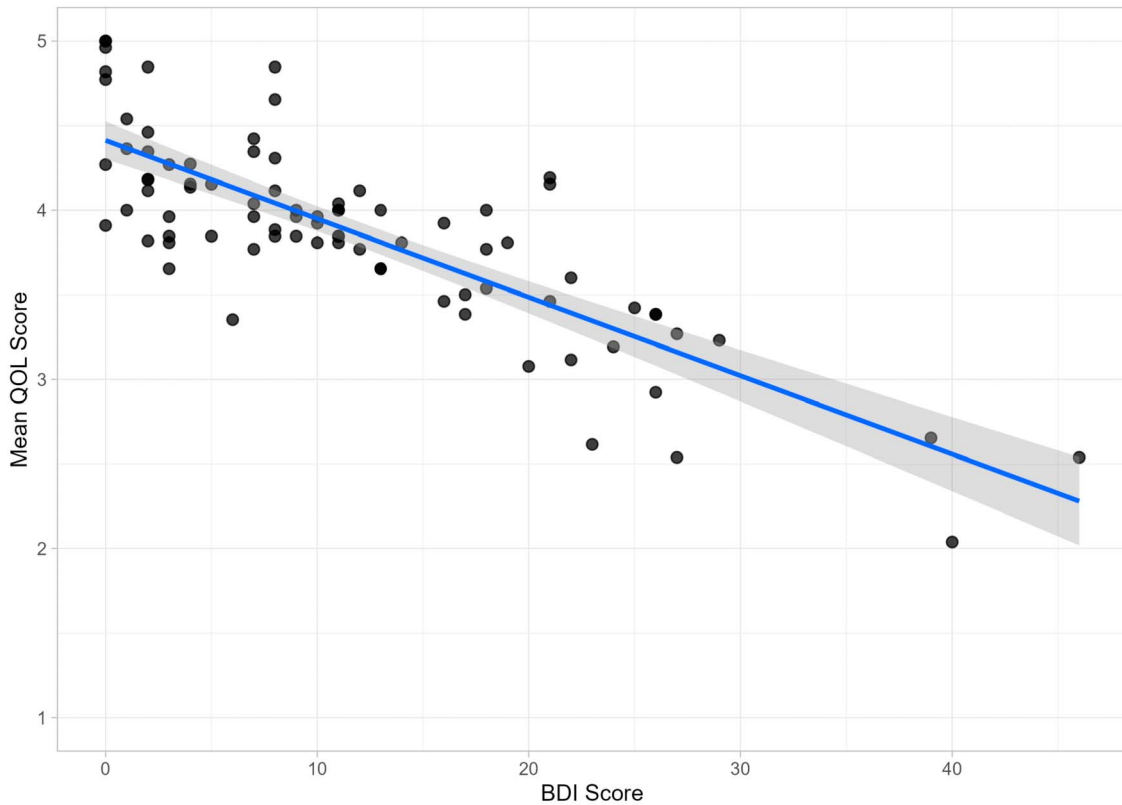
FIGURE 2. Mean QOL score vs. BDI for all visits where both scores were measured (The blue line indicates the estimate and 95% confidence interval from a simple linear regression model. Model 3 in Table 2 provides estimates for a related mixed-effects model adjusting for both BDI score and time on study.).

participants were English speakers, although the Last Gift also allows inclusion of Spanish speakers into the study. Moreover, owing to the nature of the study, time on study and extent of participation were highly variable among the participants in the UCSD Last Gift, with only 24 of the original 35 participants completing the first follow-up interview and only 20% (N = 7) completing a seventh interview. This phenomenon is called "functional attrition" and is a commonly observed in EOL research.[41] The time between each evaluation was different among the participants, affecting generalizations of the extent of time participants may have exhibited trends in QOL, depressive symptoms, or substance use. In addition, a selection or sampling bias is possible given the nature of the study's recruitment, and we further recognize that survival bias may influence QOL scores among participants who lived longer. Our study did not include a comparison group (ie, PWH at the EOL not enrolled in EOL HIV cure research).

Although the UCSD Last Gift study records information regarding indicators of various social determinants of health including housing status, health insurance coverage, monthly income, education, zip code, and approximation of one's supportive community, we lacked sufficient data to fully evaluate their effect. Other experiences including symptom presentation or perceived discrimination remained unmeasured. This observation underscores the need to collect data on social determinants of health with PWH at the EOL moving forward. Last, self-reported information comprised most of the data collected for this analysis. As a result, data may have been susceptible to social desirability bias, recall bias, or option/order bias from participants. This limits the potential to identify significant conclusions regarding long-term trends in mean QOL or BDI scores. The inverse correlation presented in this study requires further elucidation of the full scope of causative factors that influence how depressive symptoms may specifically affect QOL.

Our study presents new insights into EOL experiences among PWH but draws from a small pool of participants. Future evaluations of EOL experiences among PWH should expand recruitment and include controls (ie, people without HIV or PWH who are not participating in EOL cure-related research such as the UCSD Last Gift) to further support the significance of these findings. Further research is also needed to identify whether interventions to improve QOL may directly decrease depressive symptoms and vice versa, as such interventions could prove critical to mitigating potential disruptions in medication adherence and HIV management.

CONCLUSIONS

Our study evaluated QOL at the EOL for PWH in the Last Gift, finding a significant inverse relationship between
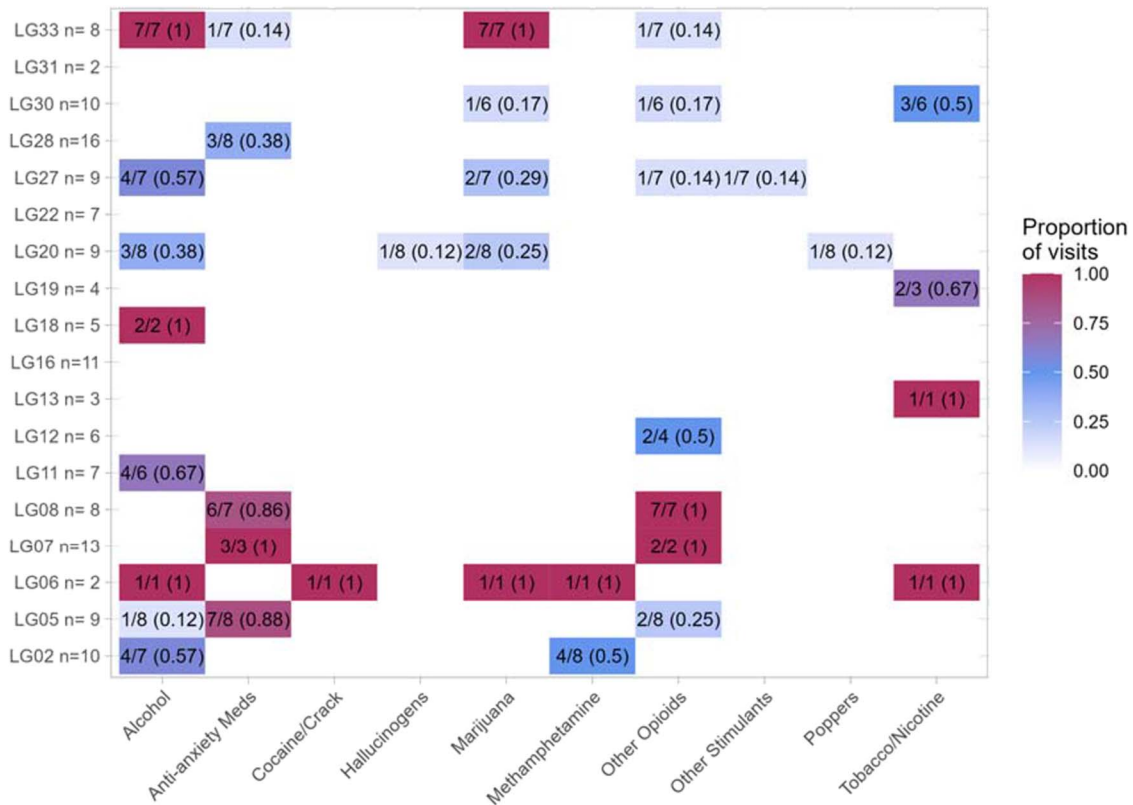
FIGURE 3. Frequencies m/M and (proportions) of visits where recent substance use was indicated (n = 18). (In each cell, "m" is the number of visits at which the participant answered "Yes" for recent use for the substance and "M" is the number at which they answered "Yes" or "No". Substances for which no recent use was reported at any assessment are left blank. The number n on the *y* axis gives the total number of visits for each participant, regardless of whether recent substance use data were collected.).

mean QOL and BDI scores. QOL at the EOL was stable at a high level among participants, who reported stable patterns for depressive symptoms throughout serial evaluations. Understanding how depressive symptoms may negatively affect QOL at the EOL for PWH is necessary to augment future research and care for this unique population.

Longer enrollment in the Last Gift study may have a beneficial effect on QOL, which may be attributed to the added sense of legacy and meaning from involvement in HIV cure research, having regular access to the Last Gift study team, and reduced social isolation at the EOL. Our findings urge further characterization of the potential positive effects of research engagement. Future interventions should aim to augment the positive effects of research engagement and improve linkages to mental health care to improve QOL among PWH at the EOL.

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