

# “My Death Will Not [Be] in Vain”: Testimonials from Last Gift Rapid Research Autopsy Study Participants Living with HIV at the End of Life

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## Abstract

End-of-life (EOL) HIV cure-related research provides a novel approach to studying HIV reservoirs. The Last Gift is a rapid autopsy research study at the University of California San Diego that enrolls terminally ill people living with HIV (PLWHIV) with a desire to contribute to HIV cure-related research. We conducted in-depth baseline and follow-up interviews with Last Gift study participants. We analyzed interview data applying conventional content analysis. Since summer 2017, 13 participants have been enrolled ( $n = 11$  males and 2 females; aged 45–89 years) and 8 participants interviewed. Terminal illnesses included cancers, heart diseases, and neurodegenerative illnesses. Our analysis revealed five key themes: (1) The Last Gift study has tremendous meaning for participants at the end of their life. (2) HIV-specific altruism was a primary motivator to join the Last Gift study, nested within the context of community, scientific advancement, and moral obligation. (3) Participants did not expect physical benefits yet they perceived emotional/psychological, financial, and societal/scientific benefits. (4) There were minimal participant-perceived risks and concerns. (5) Last Gift participants expressed immense gratitude toward study staff. The Last Gift study provides a framework for ethical HIV cure-related research at EOL and highlighted participants' perspectives, motivations, and experiences. Knowing how PLWHIV understand and experience such studies will remain critical to designing ethical, fully informed HIV cure research protocols that are acceptable to PLWHIV.

**Keywords:** HIV cure research, Last Gift, rapid research autopsy, end of life, altruism, sociobehavioral research

## Introduction

**E**ND-OF-LIFE (EOL) HIV CURE-RELATED research provides a novel approach to studying HIV reservoirs and HIV cure research strategies.<sup>1–3</sup> The Last Gift is a rapid autopsy research study at the University of California San Diego (UCSD) that enrolls people living with HIV (PLWHIV) who

have a non-AIDS-related advanced or terminal illness with a strong desire to contribute to HIV cure research.<sup>4</sup> To be eligible for the study, participants must have a prognosis of less than 6 months.<sup>2</sup> No other inclusion or exclusion criteria were considered. Last Gift participants join the study with neither expectation of direct clinical benefits nor of being cured of HIV or their terminal illness.<sup>2,5</sup>

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Antemortem participants undergo blood draws and optional biological sample collection to characterize HIV reservoirs—locations in the body where HIV remains latent<sup>6</sup>—as well as sociobehavioral interview assessments about the experiences and feelings of participating in HIV cure-related research at EOL. The primary postmortem procedure is a rapid research autopsy performed within 6 h of death.<sup>1</sup> The decision to integrate sociobehavioral assessments was motivated by the fact that EOL HIV cure-related research is novel and unique; no other data exist regarding participant experiences in or perceptions of such research. These assessments of participant reports in the Last Gift study are meant to assist in participant-centered designs of EOL studies, and to better understand participant needs, motivations, and experiences.<sup>2,7</sup> In this study, we report testimonials from the first 13 Last Gift study participants in the last few weeks of their lives.

## Methods

A study team member (S.C.G.) conducted baseline interviews shortly after participant enrollment in the Last Gift study. Baseline interviews were completed in one visit or over multiple visits given the fragile state of health of participants and the unique constraints of a study enrolling terminally ill individuals with symptoms such as intractable pain, light-headedness, and weight loss. Participants underwent follow-up interviews at periodic intervals (every 1–3 months), depending on their prognosis and time on the study. Participants were offered USD20 reimbursement for the baseline interview and USD10 for each follow-up interview. Notably, some participants explicitly refused compensation to participate in the study.

We developed interview guides in close collaboration with the AntiViral Research Center Community Advisory Board and the Palm Springs Positive Life Program. We pilot-tested in-depth interview guides with community members and revised them before the start of the study. The Last Gift study was approved by the UCSD Institutional Review Board (IRB). All participants provided informed consent to be interviewed as part of the main study protocol.

The baseline interview covered the following: demographic characteristics, motivations for study participation, attitudes toward HIV cure research, understanding of the study (including risks and benefits), perceived meaning of the Last Gift study, facilitators and barriers to participation, quality of life, and altruism. Follow-up interviews covered experiences in the study (both positive and negative), needs, regrets, and recommendations to improve the study. Questions were open-ended, and the interviewer (S.C.G.) conducted the interviews face-to-face in various environments, (e.g., bedside in the hospital or hospice facility, at participant's home, in a research office), and used prescribed probes as necessary. In-depth interview guides can be made available upon request.

After each interview, the same study team member (S.C.G.) uploaded the audio files into the secure database (REDCap, Vanderbilt University, TN), which were then transcribed to Microsoft Word with personal identifiers removed by research staff (K.P.). Transcripts were reviewed by a second research staff (H.P.) for quality control. Data from final transcripts were entered into a preprogrammed study database in Qualtrics™ (Provo, UT), a platform for gathering

and analyzing data, to facilitate ongoing review of participant responses. After transcription, quality control, and data entry were completed, the original audio files were deleted, as indicated in the IRB application.

Interview data extracted from Qualtrics into Excel spreadsheets were double-coded manually (by K.P. and K.D.) into emergent themes using an inductive approach, where specific data or quotations are analyzed to form general themes based on data patterns, as appropriate for shorter interview responses. We did not use a pre-existing coding scheme. We applied conventional content analysis, where categories for themes and subthemes are directly derived from participant interviews, to organize text units into a structured format. Our analytical methods were inspired by the phenomenological approach<sup>8</sup> in relation to study participants sharing their lived experiences in confronting death and the dying process while being in the Last Gift study. Key emergent themes and associated quotes were organized into a Microsoft Word processing document. The most salient quotes can be found verbatim in the Results section. Supplementary quotes are included in Appendix Table A1.

## Results

Since summer 2017, 13 participants were enrolled ( $n = 11$  males and 2 females; aged 45–89 years), 8 of whom were interviewed. All were Caucasian, and one was Hispanic. Terminal illnesses included cancers (e.g., brain, pancreatic, oral, rectal, and lung), heart diseases, and neurodegenerative illnesses (e.g., amyotrophic lateral sclerosis). All were first-time HIV cure-related research participants, but none was new to HIV clinical research. Given the variable prognosis of the participants, duration of follow-up varied between <1 month to 22 months (Table 1). One person declined Last Gift study participation, including the sociobehavioral component.

Our analysis revealed five key themes (Fig. 1): (1) The Last Gift study has tremendous meaning for participants at the end of their life, including the ability to find fulfillment, to be part of a collective movement, hope, and the opportunity to leave a legacy. (2) HIV-specific altruism was a primary motivator to join the Last Gift study, nested within the context of community, scientific advancement, and moral obligation. (3) Participants expected no physical benefits, yet they perceived emotional/psychological, financial, and societal/scientific benefits of the study. (4) Participants perceived minimal risks, and expressed minimal concerns for the participants and their family. (5) Last Gift participants expressed immense gratitude toward study staff in follow-up interviews.

### *Meaning of the Last Gift study*

Participants said the Last Gift study provided a sense of fulfillment and self-actualization—a sentiment that they had not expected to feel at the end of their life. The opportunity to participate in the Last Gift study provided them with meaning and an opportunity for “giving something back” [Last Gift (LG)-08, baseline interview] that was “worthwhile” (LG-11, baseline interview). For example, participants stated:

I'm grateful for the opportunity to do something that is, that will make all this [HIV and terminal illness] meaningful. (LG-05, follow-up interview)

TABLE 1. DEMOGRAPHIC VARIABLES OF LAST GIFT STUDY PARTICIPANTS (2017–2019)

<i>LG participant number</i>	<i>Sex</i>	<i>Age<sup>a</sup></i>	<i>Race/ethnicity</i>	<i>Terminal illness</i>	<i>Duration of participation in study (no. of months)<sup>b</sup></i>
LG-01	Male	58	Caucasian/non-Hispanic	ALS	1.8
LG-02	Male	50	Caucasian/Hispanic	Brain tumor	22.0
LG-03	Male	72	Caucasian/non-Hispanic	Pancreatic tumor	5.8
LG-04	Male	69	Caucasian/non-Hispanic	AML	1.7
LG-05	Male	57	Caucasian/non-Hispanic	ALS	13.2
LG-06	Male	57	Caucasian/non-Hispanic	Oral cancer	1.7
LG-07	Male	45	Caucasian/non-Hispanic	Brain tumor	16.0
LG-08	Male	52	Caucasian/non-Hispanic	Rectal cancer	2.4
LG-09	Male	80	Caucasian/non-Hispanic	Lung cancer	0.4
LG-10	Male	74	Caucasian/non-Hispanic	Liver cirrhosis	1.0
LG-11	Female	89	Caucasian/non-Hispanic	Heart failure	9.0
LG-12	Female	71	Caucasian/non-Hispanic	Breast cancer	7.0
LG-13	Male	55	Caucasian/non-Hispanic	Metastatic melanoma	3.0

<sup>a</sup>Age at enrollment.

<sup>b</sup>Last updated January 2020.

ALS, amyotrophic lateral sclerosis; AML, acute myeloid leukemia; LG, Last Gift.

It does add a little bit of meaning since I feel like I'm able to give back since originally, I didn't think I'd be able to donate my body to anybody. [The research project] makes me feel like I am giving something back towards the end of my life (LG-08, baseline interview)

[I]t means that I'm able to contribute. At the age of 89, I still have something worthwhile to give back, because I've had a good life, and, uh, being diagnosed with HIV didn't ruin my life in any way. (LG-11, baseline interview)

The Last Gift study also provided participants with a sense of hope that their involvement in the study would help humankind at large, helping pave the way for others to stay "healthy" (LG-02, baseline interview) and give them "a reason to live" (LG-02, baseline interview), which was often times associated with altruism (discussed below):

[The study] would give people a reason to live (...) a reason to want to live to...to look forward to a day when they can tell their families they are well, they are healthy. Their family and friends can take something from that. (LG-02, baseline interview)

Hope they find something with my remains that helps scientifically (LG-03, baseline interview)

I believed in this study from the first time I heard about it...I feel privileged to be a part of it. And I hope that good can come of it. (LG-05, follow-up interview)

Related to hope, many participants identified leaving a legacy as a key factor in their decision to get involved in the Last Gift study. One participant noted the connection between his life and the lives before him, and expressed a desire to "do something that will benefit those that will come after" (LG-08,

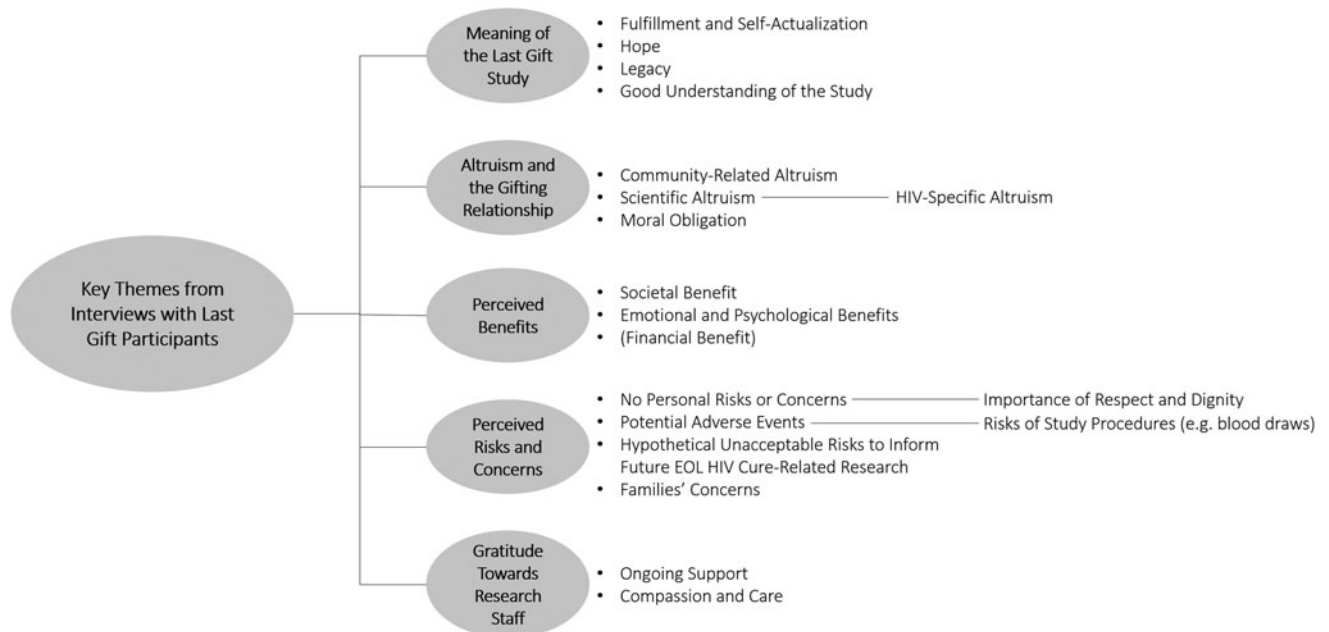


FIG. 1. Coding tree of emerging themes: in-depth interviews with Last Gift study participants (2017–2019). EOL, end of life.

baseline interview). The temporal nature behind the meaning of the Last Gift study was embodied in the legacy that participants felt they were leaving by donating their bodies to HIV cure-related science, viewing their involvement in the study as a connection between past, present, and future:

My death will not [be] in vain. It will allow me to leave a positive legacy and inspire others to give back. (LG-05, baseline interview)

The opportunity to benefit science. Do good for others. Legacy. Giving back. (LG-05, baseline interview)

Wanting to give back something before my life ends. Just wanting to know that I have been grateful for all that has happened with me in terms of HIV, and those that went before me and I wanna be able to possibly do something that will benefit those that will come after me, since I benefited [from] those who gave before me. (LG-08, baseline interview)

Some Last Gift participants expressed discontent about the casual attitude shown toward HIV today. They see their involvement in the Last Gift study as another form of activism navigating away from the perceived casualness of contracting HIV. For instance, one participant viewed their involvement in the study as a way to combat the notion that “there has become...a casual attitude about the disease” (LG-12, baseline interview):

[M]ore knowledge about the long-term impact of HIV. I think...there has become kind of a casual attitude about the disease. It's not in the forefront as it once was, and it's not...as terrifying as it once was. There are still very impactful effects on the body. (LG-12, baseline interview)

Except...I hope that a cure will not, is not a way of telling people that they can continue to live, live without no direction. You know, I hope it does the opposite of that. That it works as the opposite. That it helps them to be thankful, be thankful that there's research out there that help them get better – help them get well. (LG-02, baseline interview)

Participants articulated the meaning of the study within a scientific context, such as to “research how HIV can affect the brain and how it hides within the body” (LG-08, baseline interview). Most participants exhibited a sophisticated understanding of the Last Gift study and its purpose, explained in terms of “find[ing] a cure for HIV/AIDS” (LG-02, baseline interview), “post-mortem autopsy” (LG-03, baseline interview), and “learn[ing] about HIV at [the] end of life and where it flares up” (LG-05, baseline interview).

#### *Altruism and the gifting relationship*

Participants noted that the Last Gift study allowed them to contribute altruistically to their respective communities. One participant said he or she wanted to “help [the institution]” (LG-03, baseline interview), another to “be of assistance to people [who] have the same disease” (LG-04, baseline interview). Others voiced similar sentiments, seeing themselves positioned to contribute to a cause that others could benefit from—be it future generations or current populations of PLWHIV, as noted by other participants:

So, uh, I think the research...helps a lot of people. Even if it don't cure... you're not being a selfish individual, you know, you're...thinking of others, you're thinking of the cure that it can bring others, the happiness, is possible down the road, so you're not, you're no longer being a selfish...you're thinking of others. (LG-02, baseline interview)

To see if I could help with people with HIV and this research study. (LG-08, baseline interview)

[T]o contribute to a possibility of enlightenment for the general public and about the disease and...people living with HIV. Young people who have a long life ahead of them. (LG-11, baseline interview)

Something that I will never benefit from, but others will in the future. (LG-12, baseline interview)

Participants also expressed altruistic motivations toward scientific advancement, stating they desired to “further the knowledge” (LG-12, baseline interview) or “be a small part of [eliminating HIV] with any research with [their donated tissue]” (LG-08, baseline interview). In many cases, their personal goals were aligned with the scientific goals of the Last Gift study, as revealed when participants stated “I can be an asset to understanding the pathology of HIV” (LG-05, follow-up interview) and “whatever I can do to aid the research” (LG-12, baseline interview).

Some participants perceived the Last Gift study as a vessel for them to “[do] some good before [dying]” (LG-02, baseline interview) and as an opportunity to embody a good moral character and “erase some karma debt” (LG-11, baseline interview). The moral obligation to participate felt by some Last Gift participants was also expressed in these quotes:

I thought it, the study would do some good...I never have uh been any good to anyone or anything so, I thought this was my way of, of doing some good before I die. Giving back. (LG-02, baseline interview)

My participation in this study is a personal decision I have made and I would also note the firm belief that it's something that we have a moral obligation to do...the more people that see the need, or see the benefit, in aiding the study, the better off everyone is as a result. (LG-05, follow-up interview)

[The study] balances the periods in your life that have been unethical. (LG-11, baseline interview)

Community-related and scientific altruism and moral obligation are prominent reasons why participants are motivated to be involved in the Last Gift study, and these reasons are closely associated with the study's perceived scientific benefits.

#### *Perceived benefits of the Last Gift study*

Most Last Gift participants noted that their involvement in the study—as well as the overarching study's mission and its staff—provided a benefit to society at large. For instance, the knowledge that there are “scientists and people [who] do a good job of coming up for a cure [who] do it for each other [and] for mankind” (LG-12, baseline interview) through the Last Gift study is a benefit in itself, in addition to scientific advancement and service to humankind. Another participant stated that the study served as a “chance for possibly other people not having to get a diagnosis of HIV” (LG-08, baseline interview), inherently describing the study as a vessel of hope.

Participants did not describe any explicit physical benefits from participating in the study, and understood that the Last Gift study would not cure them of their HIV or their terminal illness; however, they did describe possible physical benefits from an eventual cure from HIV, such as being “pain free”

(LG-02, baseline interview), no longer having to “take any antiretroviral medicines” (LG-03, baseline interview), and no longer experiencing the “side effects” of medications (LG-11, baseline interview).

Participants described a variety of deep emotional and psychological benefits as a result of their study involvement. Common benefits reported included “peace of mind” (LG-05, baseline interview), the knowledge that participants were “able to contribute back” to society (LG-08, baseline interview), the ability to have “control over [the] end of life” (LG-05, baseline interview), and “the sense to further the study” (LG-12, baseline interview) in itself serving as a psychosocial benefits:

I think [the study] helps people from a...mental standpoint there, there's a positive. (LG-02, baseline interview)

It makes me feel like I'm being useful and I'm doing something good and positive. When you spend a lot of time like I have doing a lot of negative activities and negative things, it's refreshing to be able to do something positive and do something right. (LG-02, follow-up interview)

[K]nowing I'm doing good. (LG-05, baseline interview)

Being able to know that I did something with the little bit of last of my life, that I was able to contribute back in some way. (LG-08, baseline interview)

One participant noted a financial benefit as a result of study involvement, with costs of cremation being covered by the study:

To be honest, one of them was that at the end, the body will be taken care of so that my family doesn't have that expense. (LG-12, baseline interview)

Emotional and psychological benefits were clearly distinguished, and minimal physical benefits were identified.

#### *Perceived risks and concerns with the Last Gift study*

Most participants did not describe specific risks associated with the Last Gift study although some addressed the potential of unintended adverse events resulting from medical procedures such as blood draws:

I don't see any risk. (LG-02, baseline interview)

The risks are that there could be with blood draws and things like that, there could be, you know, an issue where there might be a damage, but [the Institution] would take care of me medically if there was any issue with that. (LG-08, baseline interview)

Hypothetical risks from procedures that could deter terminally ill participants from participating in HIV cure-related research in general (not specific to the observational Last Gift) included procedures that “would interfere with daily living” (LG-03, baseline interview), “hasten the end of [life]” (LG-12, baseline interview), or procedures that would result in physical atrophy, such as feeling weak, losing hair, losing weight, and losing mental capacities. Additional quotations on hypothetical risks that would be unacceptable at the EOL include:

Probably something like chemotherapy, or something like that, where it...leaves you real weak, like some cancer patients...they lose all their hair and they lose weight. Something of that nature probably make me not really be all that enthused about it. (LG-02, baseline interview)

If it were to hasten the end of your life...if they were giving you medication...I wouldn't be up for that. (LG-12, baseline interview)

However, one participant stated that the shortened time at the EOL may provide an opportunity to “take a greater risk to possibly benefit others, and [they would be] willing to do that,” (LG-08, baseline interview) illustrating a desire to choose greater risk to the body to benefit other PLWHIV in the future.

Very few participants described potential risks related to the Last Gift study. However, most participants highlighted unacceptable hypothetical risks in the name of research, such as procedures that would make participants feel weaker or that would result in loss of mental capacity at the end of their life.

Similarly, most participants described no personal concerns with study involvement, although one noted the importance of being treated with “respect and dignity” while living and after death. Other relevant quotations related to personal concerns with the Last Gift study include:

I don't really have any concerns or reservations. I think from my standpoint is all positive, all of it is positive. (LG-02, baseline interview)

None. (LG-05, baseline interview)

Just that...there's follow through, that if...if I do this study that the cremation actually happens and that my body's treated with respect and dignity. There's the only thing [my family would] be afraid of. If it would be used for something else other than the study. (LG-08, baseline interview)

Some Last Gift participants noted their families' concerns about the participants' mental health and that involvement in the Last Gift study may exacerbate their terminal illness. Most participants described feeling supported by their families, loved ones, and/or intimate partners while being involved in this study:

[My family is] all behind me 100%. They aren't concerned at all. (LG-11, baseline interview)

They are concerned about my issues with depression and that this might exacerbate that. (LG-12, baseline interview)

While a few concerns were raised (one related to participants' bodies being treated with dignity during the rapid research autopsy and cremation process, and the other related to family members' concerns), most expressed positive feelings toward the study and its research staff.

#### *Gratitude toward Last Gift research staff*

Participants expressed gratitude toward study staff in follow-up interviews, providing specific examples of moments that added value to them, stating “You greet me. You visit me in the hospital...very professional when you draw blood...those things mean a lot to me” (LG-02, follow-up interview) and:

“[S]taff shows up on time. They're always courteous. They're always concerned about my well-being. A lot of them will come to see me even though it's not related to the actual study. They just wanna make sure that I am doing well. And all of that means a tremendous amount to me.” (LG-08, follow-up interview)

In addition, participants described specific qualities in research staff that stood out to them, stating:

“I’m in constant contact with various...staff, and I’ve been shown a lot of concern and appreciation and compassion” (LG-05, follow-up interview) and “Everyone who has been associated with this study has been very kind, supportive, and verbalized how valuable my participation is and that I’m gratified” (LG-05, follow-up interview).

Gratitude toward research staff became salient in follow-up interviews, highlighting the ongoing support, compassion, and care participants felt research staff exhibited. A participant/research staff partnership built upon respect, patient-centeredness, and trust will continue to be prioritized.

Appendix Table A1 contains supplementary quotes related to the above themes.

## Discussion

The Last Gift study highlighted perspectives, motivations, and experiences that participants had as a result of their study involvement. It also underscores the significance of integrating behavioral and social sciences with biomedical HIV cure-related research, especially in research conducted among participants at the end of their life. Given the emergence of EOL research within HIV cure-related research,<sup>1,9,10</sup> the Last Gift study continues to be a unique opportunity to study participant perceptions and experiences. Specifically, our data reveal the psychosocial challenges associated with EOL, as well as the psychosocial and intangible benefits of being a part of a study during that time.

Overall, participants had clear altruistic motivations to participate in HIV cure-related research<sup>11–15</sup> as has been documented in other fields (e.g., oncology).<sup>16–18</sup> Previous scholars have also stated that PLWHIV can be involved in HIV cure-related research with informed consent, potentially at the expense of self-interest.<sup>19</sup> However, in our study, the social and science-specific aspects of altruism were clear and included love for humanity and giving back to past and future patient participants.<sup>20–22</sup> It is also important to point out that participant narratives were nested in the context of a special bond with and gratitude toward the research site/team and with the study’s scientific rationale. These sentiments highlight the importance of a participant/research staff partnership that holds patient/participant centeredness at its core.<sup>2,23,24</sup>

Altruism paired with positive study experiences enhanced the alignment between participants’ and the study’s biomedical research goals—a provision of extremely valuable information to the scientific community. Regarding scientific altruism,<sup>14,15,25,26</sup> some participants expressed a moral obligation or sense of duty to join the study, themes similarly emphasized in HIV and oncology literature.<sup>16,18,25</sup> We believe in this case their altruism may have been HIV-specific, as opposed to directed toward the terminal illness.<sup>1</sup> Participation in HIV cure-related research was also seen as a form of activism,<sup>20,27,28</sup> analogous to the early HIV epidemic in the United States where participating in treatment research to stay alive was the prevailing spirit.<sup>29</sup> However, the experiences of kindness and integrity shown to participants by research staff cannot be understated.

Importantly, terminally ill participants valued the deep sense of purpose and fulfillment in perceiving themselves as an integral part of the HIV cure-related research process. These findings align with other research describing participants’ feelings of personal empowerment, participant agency,

meaning in research participation, and contribution that PLWHIV experience regarding their involvement in HIV cure-related research.<sup>25,27,30</sup> As shown in previous similar research, hope was a key, recurring theme in HIV cure-related research participation.<sup>11,25,31</sup> Furthermore, some participants relayed a deeper appreciation in the death and dying process—regarded as a transformational experience that furthered one’s contribution to science and society even after one’s death.<sup>32–34</sup>

Participants articulated agency and motivation to participate in research<sup>25</sup> rather than passively accepting their fate. Participants understood they were entering into a gifting relationship with the institution, future patients, the general HIV cure-related research community, and the study’s research team.<sup>1,2,30</sup> Participants mentioned the opportunity of leaving a legacy as an important psychosocial benefit of being in the study. Furthermore, most PLWHIV involved in the Last Gift study had previously faced the imminent possibility of death when HIV was untreatable, and were now eager to donate to the science that contributed to them living a near-normal life despite a chronic illness.<sup>2</sup>

One research-related theme critical for the advancement of HIV cure-related research was that the Last Gift study provided no expectations regarding personal or clinical benefits, and no prospect for cure for HIV or the terminal illness/disease.<sup>2</sup> Participants did not appear to overestimate cure expectations in the study.<sup>2,35</sup> This understanding of the research benefits and risks is critical for the conduct of HIV cure-related research. However, Last Gift participants did identify potential *future* physical benefits of their participation for others (e.g., the possibility of PLWHIV not having to take antiretroviral treatment (ART), or becoming pain free 1 day). Previous research has highlighted chronic pain experienced by PLWHIV, with point prevalence ranging from 54% to 83%, particularly toward the EOL.<sup>32</sup> Notably, the Last Gift study appeared to provide emotional and psychological benefits to participants, mirroring those found in organ donation literature with living donors.<sup>36–38</sup>

Important quality-of-life EOL factors identified by previous literature that emerged during the Last Gift study included being treated as a “whole” individual, the ability to help others, having funeral arrangements, and not being a “burden to family.”<sup>39</sup> It remains unclear whether the Last Gift study alleviates feelings related to the mourning of one’s own passing, enabling the participant to ease into the process of death and dying as identified by Goodkin and colleagues.<sup>32</sup> Only one Last Gift participant perceived a financial benefit to study participation (i.e., helping with the cremation and not being a financial burden to family at the EOL), which may have been due to an unique situation. Importantly, monetary compensation did not motivate the majority of Last Gift participants; in fact, anecdotally, some refused monetary compensation for completing study procedures (e.g., specimen collections and in-depth interviews). In consultation with local community advisory boards and IRB, our study team determined that cremation should not be presented as a benefit of the study but as a necessity of the research design.<sup>2</sup>

The majority of Last Gift participants did not identify any major risks of being part of the study. Nevertheless, Last Gift participants were able to name some general hypothetical risks that would be unacceptable to them toward the EOL in the name of scientific research, including procedures that would make them feel weaker (e.g., chemotherapy), hasten

TABLE 2. SUMMARY OF FINDINGS FROM IN-DEPTH INTERVIEWS WITH LAST GIFT STUDY PARTICIPANTS (2017–2019) AND IMPLICATIONS FOR END-OF-LIFE HIV CURE-RELATED RESEARCH

<i>Summary of findings</i>	<i>Implications for future EOL HIV cure-related research</i>
<p>Meaning of the Last Gift study</p> <ul style="list-style-type: none"> <li>• The Last Gift study provided fulfillment, meaning, and self-actualization at the EOL—providing opportunities for patient/participant agency, meaning in research participation, and a deeper purpose in the death and dying process.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants' motivations, concerns, perspectives, and experiences need to be taken into account to ensure patient/participant centeredness and ethical research conduct at the EOL.</li> </ul>
<p>Altruism and the gifting relationship</p> <ul style="list-style-type: none"> <li>• HIV-specific altruism was a salient theme that dominated participants' accounts of their motivations to become involved in the Last Gift study.</li> <li>• Community-related and scientific altruism and a moral obligation to participate were prominent altruistic features articulated by participants.</li> </ul>	<ul style="list-style-type: none"> <li>• Continuing to understand how PLWHIV make decisions to participate in and their experience in EOL HIV cure-related studies is critical to ethical and fully informed research design that preserves patient/participant voice.</li> <li>• Empirical research is needed on mental health and psychosocial aspects of the EOL among HIV research participants, incorporating their cultural values, gender norms, and other more nuanced and intangible factors.</li> </ul>
<p>Perceived benefits of the Last Gift study</p> <ul style="list-style-type: none"> <li>• Deep emotional and psychological benefits were described by Last Gift participants as a result of being involved in the study.</li> <li>• Control over the EOL process and peace of mind appeared to be among the most salient benefits.</li> </ul>	<ul style="list-style-type: none"> <li>• Expectations and potential scientific benefits of HIV cure-related research at the EOL must not be oversold or exaggerated to participants. The informed consent process must be robust.</li> <li>• Psychosocial benefits and challenges must be acknowledged and appreciated through a multidisciplinary and translational EOL research framework that integrates behavioral and social sciences with biomedical research.</li> </ul>
<p>Perceived risks and concerns with Last Gift study</p> <ul style="list-style-type: none"> <li>• Participants did not describe any major risks or concerns associated with the Last Gift study, although provided perspectives on what they hypothetically would consider to be "too much risk" to help inform future EOL HIV cure-related research design.</li> </ul>	<ul style="list-style-type: none"> <li>• The deep sense of respect, trust, and partnership between research teams and participants should be prioritized to ensure patient centeredness in all research endeavors.</li> <li>• Participants' lived experiences must continue to be valued, and their bodies treated with respect and dignity in life and after passing.</li> </ul>
<p>Gratitude toward Last Gift research staff</p> <ul style="list-style-type: none"> <li>• The overarching message during Last Gift study follow-up was one of gratitude toward study staff and the fact that HIV cure-related research exists.</li> </ul>	<ul style="list-style-type: none"> <li>• A clear distinction between research and care must be ensured; yet participant/research staff partnerships built upon patient centeredness, respect, and trust must be prioritized for an ethical, fully informed research experience acceptable to participants.</li> </ul>

EOL, end of life.

the EOL process, and interfere with daily living or would mentally incapacitate them. These findings advance the literature on perceived unacceptable risks in HIV cure-related research.<sup>40</sup>

Our study team has worked hard to minimize risks to study participants, including psychosocial risks, particularly within the context of EOL HIV cure-related research. Relatedly, one participant voiced concerns about family member's feelings (i.e., a family member's concern the Last Gift study might exacerbate the participant's depressive symptoms). This finding aligns with current research on depression as a salient issue among aging PLWHIV.<sup>32,41</sup> The sole concern raised by participants regarding the Last Gift study was the requirement that their bodies be treated with respect during the rapid research autopsy and cremation processes, and that anything different would be a concern. Dignity was considered high significance at the EOL<sup>39,42</sup> and is also one of utmost importance to our study team. In preserving patient/participant centeredness, we are conscious of each Last Gift participant's specific terminal condition (for more discussion, see Ref.<sup>2</sup>).

Our study had a number of limitations. The Last Gift study, including the sociobehavioral component, encapsulates many of the challenges of conducting research with terminally ill persons, including frequent interruptions (necessary as part of prioritizing participant considerations over our research de-

sign).<sup>43</sup> Given that each participant's EOL trajectory was different and at times unpredictable, follow-up duration varied in length (<1–22 months). Given the timing of the protocol amendment allowing us to implement the socio-behavioral component of the Last Gift study, we did not formally interview the first participant (LG-01). Some participants were more willing to speak than others, and some had disabilities, inhibiting participation in the socio-behavioral component of the study (e.g., although consented, one participant was unable to speak and could not be interviewed).

We must also consider the potential for social desirability bias; benefits and harms noted in our results are rendered not fully harmonized with actuality.<sup>43</sup> Although interviews were conducted in the emotionally charged environment of the EOL, our trained interviewer (S.C.G.) attempted to mitigate any potential for inducing further grief or distress by allowing participants to answer at their own pace, rather than rushing through emotional experiences. In addition, as our study did not involve hospice or palliative care, we did not delve into specific issues related to medical care at the EOL.<sup>2,32</sup> The study was conducted with a small number of participants at one site; thus, our participant pool lacks diversity with respect to race/ethnicity. We were unable to conduct an in-depth interview with the Last Gift study decliner.

We will continue to investigate perspectives of Last Gift study candidates and participants to better understand possible concerns or negative feelings about the study. While our study findings are not generalizable to the overall population of PLWHIV, we believe they have internal validity and represent the viewpoints of Last Gift study participants. Similar EOL HIV cure-related research efforts to our study are emerging elsewhere in the United States, Canada,<sup>9,10</sup> Europe, and South Africa, which will allow for more diverse perspectives on EOL HIV cure-related research in the near future. Finally, we acknowledge that sociobehavioral science *does not* replace comprehensive neuropsychiatric assessment at the EOL.<sup>44,45</sup>

The above limitations notwithstanding, we must acknowledge the important strengths of our study. For example, Last Gift participants themselves, rather than surrogates, were involved in the interview process, emphasizing the value we placed on participants' voices.<sup>13</sup> Our study followed participants in the last few months of their lives. We also adhered to ethical research principles specific to both EOL and HIV cure-related research, placing emphasis on human primacy and dignity.<sup>2</sup>

Table 2 summarizes our key findings and possible implications for EOL HIV cure-related research.

### Conclusions

The Last Gift study provides a framework for ethical HIV cure-related research at the EOL<sup>2,9,10,46</sup> and highlights participants' perspectives, motivations, and experiences as a result of study involvement. Knowing how PLWHIV understand and experience studies will remain critical to designing HIV cure research protocols that are ethical, fully informed, and acceptable to those we wish to cure.<sup>7</sup>

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No competing financial interests exist.

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(Appendix follows →)

# Appendix Table A1

APPENDIX TABLE A1. SUPPLEMENTARY QUOTES

<i>Themes</i>	<i>Quotes</i>	<i>Type (baseline vs. follow-up)</i>	<i>Participant</i>
Meaning of the Last Gift study			
Fulfillment [self-actualization at the end-of-life]			
	P: Well, at 89 [years old], you don't have a lot to give back left I mean...you have your own problems and so you're busy taking care of your own problems...So this gives meaning because there's some little bit...there's always some little bit to give back and this is all I have right now [chuckling]. [Interviewer] Participating in this study? [LG11] Participating in this study gives my life a little bit of a boost in meaning	Baseline	11
	P: I recent lost my husband...I was wondering in my mind why I'm still here at 89 and my...infectious disease doctor informed me of this, um, study that was being done...I saw it as a way for my remaining life to be meaningful	Baseline	11
	P: the possibility of contributing...as somebody has to be the subject of the research and it might as well be me because I'm at the end of my life anyway	Baseline	11
Hope			
	P: The research people will come up with a cure through studying me, through studying others like me, through studying the disease itself and all that entails	Baseline	2
	P: That it would do good. It'd be a positive. It would raise people's hopes that maybe 1 day, there is, there will be a cure	Baseline	2
	P: I would like to see a cure for all the people who are in the closet with it	Baseline	11
Legacy			
	P: ...I feel honored to have been a part of it and have part of my legacy being to help researchers and scientists...	Follow-up	5
	P: I'm just really thrilled that I am able to be a part of a program that's going to hopefully do some good in the future...and my little small part in it might make some sort of difference in how that outcome is	Follow-up	8
	P: ...my doctors and said that it would be an opportunity where...my body could be used for something possibly good in the future...	Baseline	8
Perception of scientific purpose behind Last Gift			
	P: The study is to research how HIV can affect the brain and how it hides within the body and being able to find out, even after being considered maybe undetectable, where is this virus hiding and in what tissues or where—so that we can better fight the virus	Baseline	8
	P: ...to identify where and what the virus does to the body.... I'm very much interested in the brain, because I have noticed a marked decline in my intellect, and I don't know whether I can attribute that solely to HIV. But I know that age is a factor	Baseline	12
Altruism and the gifting relationship			
Altruism for community			
	P: ...I just keep in mind it is for the benefit of people that are just like me	Follow-up	2
	P: Altruism, wanting to help, being able to give back, and having a legacy of purposefulness	Baseline	5
	P: It means that maybe someday there will be a cure, if not for myself, for all the other people that need it	Baseline	11
Altruism for science			
	P: To benefit science, to understand HIV and its effects on the body, and to find a cure. Medical research is key to understanding disease and pathology of disease and find a cure	Baseline	5
	P: ...I am participating in the Last Gift study and benefitting the research that's being done, and I can be an asset to understanding the pathology of HIV and I'm in a unique position to do that	Follow-up	5
	P: It means a lot, it means that hopefully we can eradicate HIV and if I can be a small part of that with any research with my tissue or my body, I think it's a great thing	Baseline	8
	P: I would hope that someday they would have a vaccine for, uh, HIV illnesses	Baseline	11

(Appendix continues →)

APPENDIX TABLE A1. (CONTINUED)

<i>Themes</i>	<i>Quotes</i>	<i>Type (baseline vs. follow-up)</i>	<i>Participant</i>
Altruism as moral obligation			
	P: I just knew it was something that was the right thing to do, that it would help, it would help others that came along after me or during my life or after my life. There would be something positive anytime you can find a cure for anything, cancer, AIDS, you know, it's a good thing	Baseline	2
	P: ...I'm fulfilling a moral obligation and it makes me very proud...I think we all have an obligation to help others and as others have come before me to advance science by donating their bodies after they die, we wouldn't be here without those people who came before me. So, I'm building on that legacy, and I think we all have an obligation to help others, so I feel like I'm fulfilling that obligation by participating	Follow-up	5
Perceived benefits of the Last Gift study			
Personal benefit			
Physical benefit			
	P: Not having to take the medication, mostly. And not having to feel the side effects of the faintness, the tiredness...[future benefit]	Baseline	11
Emotional/psychological benefit			
	P: Any time...something positive is happening, it makes you, it makes you think positive and think positive about it. Otherwise, it would be like no hope, be like no hope which would be a terrible thing	Baseline	2
	P: It gets me talking about my condition and I'm able to open up...I'm comfortable and can open up better	Follow-up	2
	P: Control over end of life	Baseline	5
	P: I'm benefitting from this study because it helps me to know that I'm doing something positive	Follow-up	5
	P: Mentally, I am benefitting knowing that I am contributing to the research that will hopefully result in a cure	Follow-up	5
	P:...you could talk to your friends and neighbors about being HIV+ just like you talk about having cancer or [chuckling] or whatever infectious disease but now you keep it in to yourself...I want to be free and open about what's going on [future benefit]	Baseline	11
	P: It could be just the sense to further the study...would be a benefit, an emotional benefit	Baseline	12
Financial benefit			
	P: ...the benefit of the Last Gift helping me with the cremation of my body	Baseline	8
Societal benefit			
	P: A chance for possibly other people not having to get a diagnosis of HIV	Baseline	8
Perceived risks and concerns with the Last Gift study			
Participant-perceived risk			
	P: None	Baseline	5
	P: I'm not seeing any risks involved	Baseline	12
Participant-perceived too much risk			
	P: To be mentally incapacitated, if there was a treatment or medicine that would cause me to lose my mental capacity	Baseline	5
	P: You know, I think that when you have a very shortened amount of time in life you're willing to maybe take a greater risk to possibly benefit others, and I'm willing to do that	Baseline	8
	P: I don't see any risk. I'm serious. I mean, the risk of something happening on the road is much greater than anything happening to me from this study	Baseline	11
Familial concerns			
	P: [My mom] will be all for it as long as it makes me feel positive about myself, feel like I'm doing something good. I think she'll be all for it cause she's...real high on me if I'm gonna...die. She's real high on me being positive, not being depressed and gloomy all the time	Baseline	2
Personal concerns			
	P: I don't have any concerns or reservations. It's just that these things tend to move slowly and, um, we tend to want them to come too fast	Baseline	8

(Appendix continues →)

APPENDIX TABLE A1. (CONTINUED)

<i>Themes</i>	<i>Quotes</i>	<i>Type (baseline vs. follow-up)</i>	<i>Participant</i>
Gratitude toward Last Gift research staff			
	P: I feel that the administrators of this study are very sensitive to my needs, my medical condition, and the unique qualifications that I bring to participating in this study. I feel very appreciated	Follow-up	5
	P: I feel like everybody's been treating me very well, and I feel very appreciative for participating by the entire staff, nurses, administrators, doctors, researchers. I feel very appreciated	Follow-up	5
	P: You guys rock, and thank you so much for the hard work that you guys do to help push research into this area	Follow-up	8

LG, Last Gift.