

Perceptions of Next-of-Kin/Loved Ones About Last Gift Rapid Research Autopsy Study Enrolling People with HIV/AIDS at the End of Life: A Qualitative Interview Study

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Abstract

A growing number of people living with HIV/AIDS are participating in HIV cure-related research at the end of life (EOL). Due to the novelty of EOL HIV cure-related research, there is a need to understand how their next-of-kin (NOK) perceive such research. We conducted in-depth interviews with NOK of the Last Gift study participants at the University of California, San Diego. The Last Gift study occurs in the context of the EOL and involves a full body donation. NOK completed two interviews: (1) shortly after the participants' enrollment in the study and (2) following death. We applied thematic analysis to analyze qualitative data. NOK included seven individuals (five males and two females), including two spouses, one ex-partner, one sister, a grandmother/grandfather, and a close friend. Thematic analysis revealed five key themes: (1) NOK viewed the Last Gift program in a positive light and had an accurate overall understanding of the study; (2) NOK identified factors that motivated participants to donate their body to science; (3) NOK identified benefits of the Last Gift program for both the donors and themselves; (4) NOK did not perceive any physical risks or decisional regrets of study but wanted to minimize psychosocial impacts and ensure the dignity of participants at all times; and (5) NOK noted elements that remained essential to the successful implementation of EOL HIV cure-related research, such as early involvement and clear communication. Our study uniquely contributes to increased understanding and knowledge of what is important from the point of view of supportive NOK to ensure successful implementation of EOL HIV cure-related research. More research will be needed to understand perspectives of less supportive NOK.

Keywords: HIV cure research, next-of-kin/loved ones, Last Gift, rapid research autopsy, end of life, socio-behavioral research

Introduction

A GROWING NUMBER OF PEOPLE living with HIV/AIDS (PLWHA) participate in HIV cure-related research at the end of life (EOL).^{1,2} Modeled after rapid research autopsy programs in oncology,³ the Last Gift is a clinical research

study at the University of California, San Diego (UCSD) enrolling altruistic PLWHA who have a non-HIV-related terminal illness as determined by their primary care physician.⁴ Terminal illnesses have included neurodegenerative diseases [e.g., amyotrophic lateral sclerosis (ALS)], advanced heart disease, and solid organ cancers. The Last Gift

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study does not involve palliative or hospice care, and participants have no expectation of medical benefits—for neither their HIV nor their terminal illness.⁵ Full body donations allow HIV researchers to estimate the size and location of the reservoir dynamics—how HIV persists in tissues and hides—a critical gap that must be closed to advance HIV cure-related science.⁶

The success of the Last Gift study depends on a highly organized team, robust community engagement, and positive perceptions of premortem procedures and postmortem body donations by the donor’s physician and the next-of-kin (NOK)/loved ones (hereafter referred to as “NOK”).^{7,8} Ensuring the acceptance of NOK and community stakeholders represents one of our five core ethical values for EOL HIV cure-related research.⁵ In the Last Gift study, NOK play a vital role, including serving as caregivers to the participants, carrying out participants’ last wishes at the EOL, and ensuring the body donation takes place within 6 h of death. The Last Gift study holds a broad definition for NOK—beyond biological understandings of family. NOK may include partners/significant others, blood relatives, friends, or close acquaintances who maintain distinctly close relationships with participants throughout the study.

Due to the novelty and potentially controversial aspects of EOL HIV cure-related research such as the need to donate one’s full body at the time of death,⁵ there is a need to understand NOK perceptions of such research. A close examination may inform efforts to improve research conduct. We implemented an in-depth interview with NOK of the Last

Gift study participants to understand their perceptions and the psychosocial dimensions of program participation. Sociobehavioral assessments were motivated by the paucity of data regarding NOK around rapid research autopsy programs. Based on initial interactions with NOK at the beginning of the Last Gift study, we anticipated that NOK would provide important insights into how the study could be improved. In this article, we report emerging themes from our initial in-depth interviews with supportive NOK involved in the Last Gift study (Fig. 1).

Materials and Methods

Last Gift participants composed of eight males aged 45–72 years who passed away due to neurodegenerative disease (e.g., ALS) and cancer (oral, brain, pancreatic, rectal, and acute myeloid leukemia). Most were active in the HIV activist movement or in their local community. Last Gift participants provided the names and contact details of NOK who facilitated their participation in the study. An experienced interviewer (S.C.-G) conducted two in-depth semi-structured interviews with NOK: (1) shortly after Last Gift participants’ enrollment in the study, following the terminal diagnosis (Part I), and (2) after participant death (Part II). Interviews lasted between 25 and 65 min, and NOK were reimbursed \$USD 20 for each interview.

In close collaboration with the UCSD-affiliated AntiViral Research Center Community Advisory Board and the Palm Springs Positive Life Program, composed predominantly

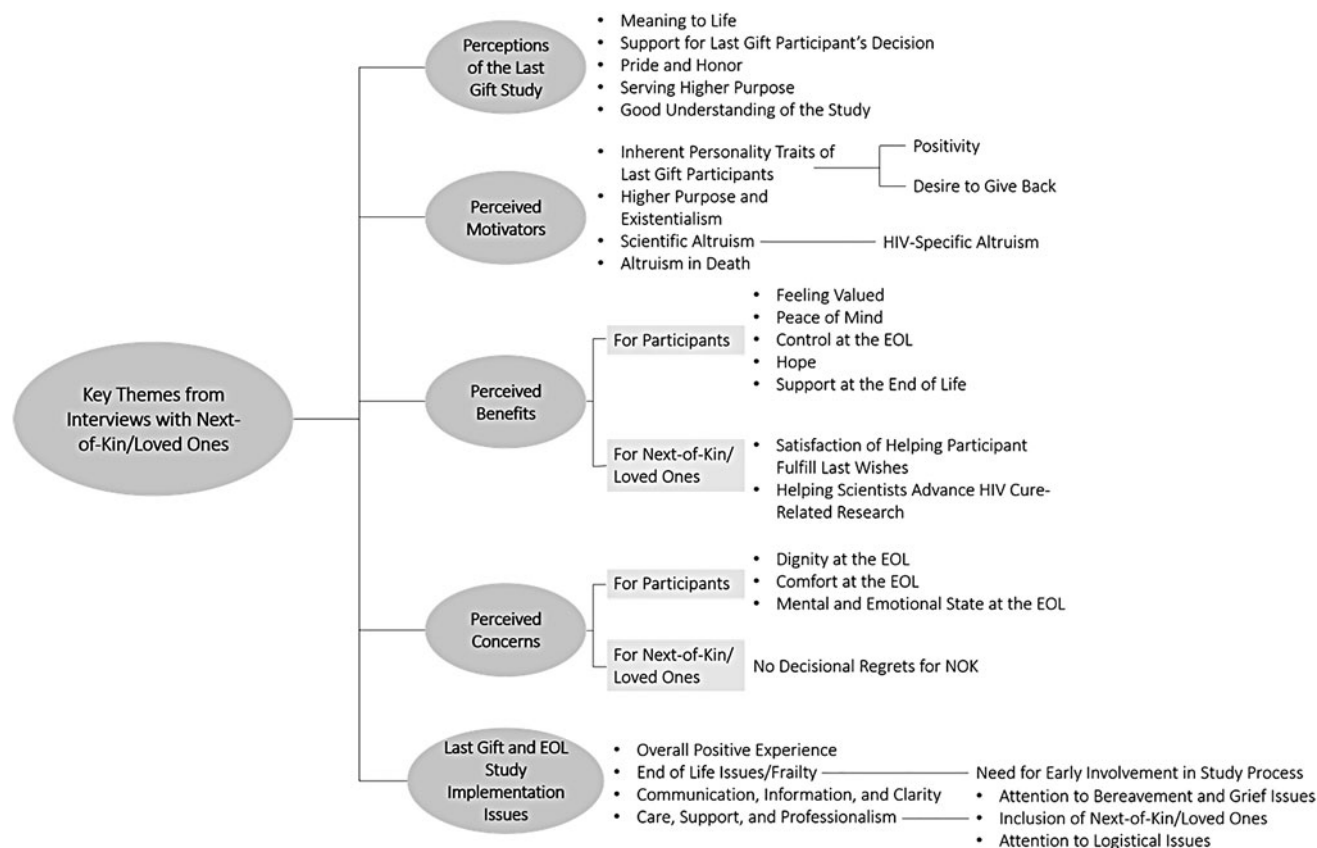


FIG. 1. Coding tree of emerging themes—in-depth interviews with NOK of Last Gift participants 01–08. NOK, next-of-kin.

TABLE 1. NEXT-OF-KIN INTERVIEWED FOR LAST GIFT PARTICIPANTS 01–08 (SAN DIEGO, CA, 2017–2019)

Participant No.	Sex	Race/ethnicity	Relationship to Last Gift participant	Part I interview (premortem)	Part II interview (postmortem)
LG-01-NOK	Male	White	Spouse	—	X
LG-02-NOK	None	None	None	None	None
LG-03-NOK	Male	White	Spouse	X	X
LG-04-NOK	Male	White	Ex-partner	X	X
LG-05-NOK	Female	White	Sister	X	X
LG-06-NOK	None	None	None	None	None
LG-07-NOK-I	Female	White	Grandmother	X	—
LG-07-NOK-II	Male	White	Grandfather	X	—
LG-08-NOK	Male	White	Close friend	X	X

LG, Last Gift; NOK, next-of-kin.

of older people living with HIV, we developed two in-depth interview guides for NOK: pre-mortem and post-mortem. We thoroughly reviewed interview guides with community members and revised iteratively before study start. In-depth interviews received approval by the UCSD Institutional Review Board (IRB). All NOK provided consent to participate in the Last Gift study and to be interviewed.

Premortem interviews covered the following topics: demographic characteristics, attitudes toward HIV cure-related research, perceived decision-making process leading Last Gift participants to join the study, understanding of the study, perceived benefits and risks, and perceived facilitators and barriers. Postmortem interviews started with a general discussion about how the NOK was doing following the Last Gift participant's passing and then went on to cover perceived benefits and risks, perceived facilitators and barriers, and suggestions to improve the conduct of the study.

Following each interview, a member of the study team (S.C.-G.) uploaded audio files into a secure server (REDCap; Vanderbilt University, TN). A research assistant (H.P.) transcribed each interview *verbatim* using the interview guide as a template in Microsoft Word. A research associate (K.E.P.) reviewed the transcripts against the audio files as a quality control step. We did not return transcripts to NOK for verification. Research staff entered data into a separate study database in Qualtrics™ (Provo, UT). Source audio files were deleted from the REDCap server after transcription, quality control, and data entry steps were completed according to the IRB-approved informed consent form and our work instructions.

Data analysis involved extracting and organizing transcript data from Qualtrics into Excel spreadsheets, followed by manual double-coding (K.D. and H.P.) of text units into emergent themes. The first coder (K.D.) organized the main themes and corresponding text units, and the second coder (H.P.) reviewed for accuracy. Discrepancies were resolved by consensus. Due to the novelty of EOL HIV cure-related research, we did not use an *a priori* coding scheme. We employed an inductive approach inspired by the phenomenological approach,⁹ consistent with NOK sharing their personal experiences dealing with the EOL process. The phenomenological approach allowed us to focus on NOK narratives and to understand their experiences through their stories, without a predetermined framework. We applied thematic analysis to document patterns and themes across NOK accounts. Relevant quotes were organized into a structured format in Microsoft Word. The most salient quotes are

included in the Results section. Supplementary quotes can be found in Appendix Table A1.

Results

In this article, we report data from in-depth interviews conducted with the NOK of the first eight Last Gift (LG) study participants (LG-01–LG-08). NOK interviewed included seven individuals (five males and two females), including two spouses, one ex-partner, one sister, a grandmother/grandfather, and a close friend (Table 1). One participant (LG-07) referred two NOK for the study. Two participants (LG-02 and LG-06) did not refer an NOK for the study.

NOKs perceptions and understanding of the Last Gift study

All NOK stated that contributing to HIV cure-related research was positive and meaningful for the Last Gift study participants. They viewed the Last Gift program as adding tremendous meaning to the lives of their loved ones at a fragile time. The Last Gift study provided a way to be remembered in a positive way.

“[W]ith this program he was over the moon, thrilled, that he was the first patient to go through it and it really gave meaning to his life”—LG-01-NOK (Spouse) Part I

“[Last Gift participant] didn't want to be forgotten and he didn't want his life to have no value (...) I want him to be able to live on through people's memories or through research that people have done”—LG-08-NOK (Close Friend) Part II

NOKs positive reactions translated into supporting the decision of their loved ones to participate in the Last Gift study.

“In our relationship I always wanted him to have the best and there were times where I felt that I could not provide for him and this Last Gift study provided for him something that I couldn't give him and I know that he was besides himself with happiness and joy and just knowing that he could do something that would benefit the rest of the world and that made me very happy”—LG-01-NOK (Spouse) Part II

“[T]hey would basically cut up his body and use whatever they could [um you know] and he kinda wanted to make sure I didn't have a problem and I said that's his body and if that's what he wanted them to do them that was his body to do it”—LG-04-NOK (Ex-partner) Part I

NOK expressed feeling pride in the Last Gift participants for donating their bodies to science. They viewed the program as a way of leaving a positive legacy.

“I am very proud of him (...) to think that it’s going to help others is a great legacy for him to leave with us”—LG-07-NOK-I (Grandmother) Part I

“Very honored and proud that [Last Gift participant] volunteered to help out with this research to find a cure and where the virus is stored in the body”—LG-03-NOK (Spouse) Part II

NOK displayed a generally accurate understanding of the Last Gift study’s purpose, including that the participants would not undergo any curative procedures. They understood that full body donation at the EOL was the main procedure.

“The Last Gift study, as new as it is, was the opportunity to provide information through someone’s death and donation of their body within a given period of time”—LG-01-NOK (Spouse) Part II

“I mean HIV hides in tissues so the most obvious way is looking through those tissues to see where HIV is hiding so I know [Last Gift participant] wanted to provide information about that”—LG-08-NOK (Close Friend) Part II

Overall, NOK reactions toward the Last Gift study were overwhelmingly positive, and this translated into support for Last Gift participants’ decisions, and pride and honor at contributing to the EOL translational research program. All NOK understood that the study aimed at studying HIV reservoirs and that cure was not an expected outcome.

Perceived motivators for Last Gift participants

We asked NOK to cite possible reasons why Last Gift participants decided to join the study. NOK discussed the inherent personality traits of the donors, such as positivity, courage, generosity, and the desire to help others.

“[Y]ou would never know [Last Gift participant] had it [HIV], I mean he doesn’t [uh, you know,] dwell on it or he’s just a very positive person—that’s one thing I love so much about him”—LG-04-NOK (Ex-partner) Part I

“Knowing that all along he’s been doing something for somebody else because that’s the kind of person he is”—LG-08-NOK (Close Friend) Part I

A common perceived reason for joining the study was the opportunity to serve a higher purpose and to add value to a life already well lived. NOK also believed the Last Gift study allowed participants to turn their HIV-seropositive status into a positive and view their life with illness as meaningful, almost as a form of existentialism.

“A sense of purpose, self-actualization, meaning, contribution, [um] validation for having become HIV infected and maybe creating a sense of reason of why they did and how they can you know have taken a negative and turn it into something more beneficial because he’s so secretive about his HIV”—LG-08-NOK (Close Friend) Part I

“I know that all people as they go through life wonder what it is that they can do for others to make their life worth living and this opportunity was presented to [Last Gift participant] and myself and he was very excited about doing it because he thought that a lot could be learned from him”—LG-01-NOK (Spouse) Part I

NOK recognized that a key motivator for joining the Last Gift study was the desire to contribute to HIV cure-related science, a form of scientific altruism.

“[T]his meant very much to [Last Gift participant] to be able to donate his body and to help and research to study and [help] find a cure for HIV”—LG-03-NOK (Spouse) Part I

“[H]e has been HIV positive some thirty years and if he can contribute to any research that can cure HIV and AIDS then he will do so. If his body and [um] remains after his death can be contributed to [Institution]’s progress in finding a cure for HIV and AIDS he will ... he is very willing to participate and give whatever he has to give”—LG-05-NOK (Sister) Part I

Even though the Last Gift study participants were dying due to a non-HIV terminal illness, their altruism leaned toward HIV because they had lived with HIV for a longer period of time, although some of the Last Gift participants became advocates for both their HIV and their terminal illness during the course of the study. NOK viewed the Last Gift study participation as specifically benefiting the community of PLWHA.

“I know that’s very, very important to him and [um] because he saw lots of friends that have passed from this terrible disease”—LG-04-NOK (Ex-partner) Part I

“He has ALS [amyotrophic lateral sclerosis] and his disease process is progressing rapidly and he knows that there is no cure for ALS and therefore he also has had HIV some quite some time (...) [he wants] to donate his remains to any research that can be done for HIV research”—LG-05-NOK (Sister) Part I

NOK viewed the Last Gift study as an opportunity to continue helping others even after the participants had passed. Altruism in death was a prominent theme throughout the interviews with NOK.

“What better way to leave this world and go to the next by still helping others or hopefully helping others by willing your body to science. I just think that was the icing on the cake of his life”—LG-04-NOK (Ex-partner) Part II

“Only in the last few days for [Last Gift participant] he was very positive and very happy that he could provide himself for this program (...) He was given the opportunity to give up himself and aid in research in hopes that they could find the answers through him and his death and that’s what made him feel better, that he knew he was able to contribute”—LG-01-NOK (Spouse) Part II

Main perceived motivators for joining the Last Gift study included positive personal traits, the desire to serve a higher purpose and altruism—including scientific altruism, HIV-specific altruism, and altruism in death.

Perceived benefits of the Last Gift study

We asked NOK to identify benefits of the Last Gift study for the participants and themselves. Perceived benefits for the donors included feeling valued, peace of mind, and control the EOL, as well as hope and support during the dying process. Exemplary quotes illustrating how NOK perceived Last Gift participants felt valued toward the EOL included:

“I know [Last Gift participant] felt valued, you could see it in his eyes, you could see it in his smile, and you could see it when he talked to us and the tears that he shed because he was so happy”—LG-01-NOK (Spouse) Part II

“The celebration of life. (...) He had in mind that he wanted for himself, a celebration of life that would bring together his friends. (...) It was beautiful, it was very, very beautiful. He was very satisfyingly touched and I think the

Last Gift was sort of ... that final closure that even though his life was short, it still had value despite the circumstance and other people that would benefit physically from learning about his body”—LG-08-NOK (Close Friend) Part II

From the perspectives of NOK, the Last Gift study provided an essential sense of closure, peace of mind, and control at the EOL, a time when physical capacities were in decline.

“A peace of mind that he’s contributing to research that may cure or control HIV in the future for people that have it [HIV]”—LG-05-NOK (Sister) Part I

“I think [the um] he’d be more comfortable towards the end of his life knowing that he’s doing this”—LG-08-NOK (Close Friend) Part I

“That he had control over [um] his [um] end and he could make it as peaceful as he wanted it to be”—LG-05-NOK (Sister) Part II

Another perceived benefit of the Last Gift study related to the hope for scientific advancement toward an HIV cure.

“HIV cure research means that the research will develop and hopefully create a cure for all that are affected by HIV”—LG-05-NOK (Sister) Part I

“The study they’re doing is going to help others that have AIDS and [uh] probably make a better, easier life for them”—LG-07-NOK-I (Grandmother) Part I

NOK felt that study participants were supported throughout their terminal illness and their dying process. The Last Gift study provided comfort and helped ensure participants were not isolated at EOL.

“Throughout his whole dying experience, it was very clear that the Last Gift was a support system that was there to sort of support him while he died, visit him, not just take his blood, but befriend him [um] spend time with him at hospice (...) provide him with emotional support that he really needed”—LG-08-NOK (Close Friend) Part II

“I feel that the Last Gift team provided the intimate, emotional support that without that, the dying experience would have been a very, very cold and lonely one. But because the Last Gift was so present, it provided sort of a cradle of comfort for both [Last Gift participant] and for all the people that were involved in his dying process until the very last minute”—LG-08-NOK (Close Friend) Part II

NOK also identified benefits of the Last Gift study for themselves as caregivers. Two main subthemes emerged: the satisfaction of being able to help Last Gift participants fulfill their last wishes, and contributing to helping advance HIV cure-related research.

“I was very happy that I was there (...) I was glad that I could be there and make sure that you guys knew when he passed because he was so worried about you know not being able to donate his body, that it would be too long”—LG-04-NOK (Ex-partner) Part II

“I did personally benefit from it. It made me feel good that [Last Gift participant] was able to give up himself so freely to provide information and that made me feel good”—LG-01-NOK (Spouse) Part II

“The same way that [Last Gift participant] did, again as my partner I felt that this was a honorable contribution to science and the HIV community”—LG-03-NOK (Spouse) Part II

From the perspectives of NOK, the Last Gift study provided psychosocial benefits for participants and NOK as they journeyed through the dying process together. Positive effects such as peace of mind, feelings of control, hope, and support were manifest throughout the NOKs accounts.

Perceived concerns of the Last Gift study

NOK did not perceive any physical risks of the Last Gift study for the participants. Main concerns for the volunteers included the psychosocial impact of being part of a study for terminally-ill individuals, the need to prevent sadness, as well as death-related distress.

“I really don’t have any concerns like I said I think it’s wonderful that he’s agreed to do this”—LG-07-NOK-I (Grandmother) Part I

“The effect on his psychological well-being. Fear it might cause depression”—LG-03-NOK (Spouse) Part I

“[W]e understand what our role was regarding his mental care during the end of life period”—LG-03-NOK (Spouse) Part II

Due to the frailty of Last Gift participants toward the EOL, NOK wanted to ensure that discomfort would be minimized and that the study would not interfere with palliative or hospice care needs.

“I don’t know that I have any concerns like the only concern that I have had is [um] any discomfort that he might experience (...) I just want to keep him comfortable”—LG-05-NOK (Sister) Part I

“I was concerned that they were going to come and draw blood from him when he just could not even have anyone around, but that wasn’t the case. [Um] I was concerned that in his most frail state that some people would be interjecting themselves to take vials of the blood but that wasn’t the situation at all. They were very respectful”—LG-08-NOK (Close Friend) Part II

Related to the theme of maintaining comfort for Last Gift participants, NOK wanted reassurance that volunteers’ dignity would be maintained throughout the entire study and after death.

“[I]t ultimately gave me comfort that he was able to pass in a dignified, loving manner (...) it was a loving peaceful death and that brings me comfort”—LG-05-NOK (Sister) Part II

“I just wanted to make sure that it was something that (...) they respected his body (...) that it was a well-organized and respected organization that was taking his body for [the] study you know ... they weren’t just desecrating his remains”—LG-08-NOK (Close Friend) Part I

We also asked NOK if there were any negatives of the study for themselves or other family members or friends. Most NOK had minimal concerns about the study; however, some emphasized the need to protect privacy and confidentiality because HIV is still a stigmatized condition in some contexts.

“No negatives at all, working with you was very easy and when I got emotional then we took a break”—LG-04-NOK (Ex-partner) Part II

“My friends and family I guess don’t know that he’s enrolled in this study so that’s something personal for him and me. They know he’s willed his body to science but I didn’t specifically say what the program was”—LG-04-NOK (Ex-partner) Part I

“[H]e’s always sort of presented this as a cancer study not for people who have HIV ... not just because he has HIV. I don’t feel that he’s comfortable discussing that aspect of his history”—LG-08-NOK (Close Friend) Part I

Overall, NOK did not report any decisional regrets from Last Gift participants or for themselves. They were glad to have been able to contribute to the program. One unavoidable drawback mentioned was that Last Gift participants would not be alive to see the results of the study.

“No I was glad that I could be there to support [Last Gift participant]. No I had no regrets”—LG-03-NOK (Spouse) Part II

“Not at all. It gave him you know something to fight for towards the end”—LG-04-NOK (Ex-partner) Part II

“If he had any regrets it would have been that he couldn’t be alive to see that the results that he provided were doing good for others”—LG-01-NOK (Spouse) Part II

NOK concerns related to the Last Gift study were minimal. Perceived concerns centered around minimizing psychosocial impact, ensuring comfort and dignity of the participants, and maintaining privacy and respect. NOK did not report major decisional regrets for the participants or themselves, except that their loved ones would not be able to witness their unique contribution to science.

EOL HIV cure-related research implementation issues

NOK noted that the overall Last Gift study experience was positive, although emotional at times, particularly after Last Gift participants had passed away. Factors that contributed to the success of the study included a personalized and reciprocal approach.

“I really didn’t know what to expect. I didn’t think that it was going to be this personal. I thought it was going to be more transactional but it wasn’t. It definitely (...) seemed to be very individualized. You’re really amazing about remembering all the details about [Last Gift participant], which is fantastic because it makes him not just a lump of flesh that you need to dissect, but a human that had an experience, that was valued”—LG-08-NOK (Close Friend) Part II

“I thought it was going to be much more signing of documents but it wasn’t. It was extremely personal, both for [Last Gift participant] and for me and making sure it was reciprocal, it wasn’t just taking from [Last Gift participant], it was supporting [Last Gift participant] and the people around him”—LG-08-NOK (Close Friend) Part II

When asked how the Last Gift study could be improved, NOK noted wanting to be involved as early as possible in the process.

“I would have liked to [have] been brought into the process probably from Day 1 when his primary doctor discussed it with him and [uh] I would have like to [have] understood the program earlier (...) I just would have liked to have been in on it from the very beginning”—LG-03-NOK (Spouse) Part II

“Just keep doing what you’re doing, being inclusive with the partners [um] give your understanding and concern and love and I know that you did that and that’s all I ask”—LG-01-NOK (Spouse) Part II

In addition to early involvement, NOK noted the importance of clearly communicating information with Last Gift participants and with the staff as a factor ensuring study success.

“I can’t think of anything that they could have done better. They were informative, they kept me up to date, they kept [Last Gift participant] up to date, [um] I don’t know of anything they could have done better, I really don’t”—LG-01-NOK (Spouse) Part II

“I think I could use more information, such as details about [um] how he would be taken care of at the very end and [how] his comfort would be cared for”—LG-04-NOK (Ex-partner) Part I

NOK appreciated knowing exactly what to do when Last Gift participants passed. They also recognized how the Last Gift study helped resolve EOL issues. The study provided a clear pathway on how to proceed following death.

“I’m his primary care directive (...) we went through pages of scenarios and what his wishes were so I’m very clear what he wants from the end of life, very clear”—LG-08-NOK (Close Friend) Part I

“[I]t resolved a lot of end of life things that needed to be done like if he was going to be buried or if there was going to be a wake, it was very resolved. So he knew that all he needed to do was to pass and everything else would be taken care of”—LG-08-NOK (Close Friend) Part II

Even though the Last Gift study did not involve palliative or hospice care, NOK acknowledged that the research staff provided valuable emotional support throughout the EOL process. Attention to emotional and psychosocial aspects contributed to the grieving process in a positive way. The importance of emotional support was particularly salient in the postmortem interview conducted with LG-08’s NOK (Close Friend):

“Extremely supportive. [Um] sort of walk[ed] me through what all the steps were that were needed after he died because I was unsure, I had no idea what to do so it provided a lot of comfort and guidance as to the next steps, [um] and some closure”—LG-08-NOK (Close Friend) Part II

“Yes, of course. [Um] I feel like I developed a friendship with the people of this study and that I could trust them and that they were not only concerned about [Last Gift participant] but that they were also concerned about me”—LG-08-NOK (Close Friend) Part II

NOK valued the emotional care and support provided by the Last Gift study team. They also appreciated the professionalism displayed by the research staff at each step of the process.

“[T]he entire experience was very professional, very caring, very loving, and everything met my expectations as we went through the final phase of [Last Gift participant]’s life”—LG-03-NOK (Spouse) Part II

“The professionalism of everyone that we dealt with was outstanding even before the procedures were drawn up (...) I can’t honestly say that they missed anything”—LG-01-NOK (Spouse) Part II

“The gentlemen (...) that did take his body ultimately were very polite and understanding and they were very, very gracious when they did come to take his body away”—LG-05-NOK (Sister) Part II

Finally, NOK appreciated the clarity around the logistical aspects of body donation. They were mostly concerned about the 6-h time frame allotted between the passing of the Last Gift participants and the body donation to ensure preservation of tissues. One NOK appreciated having the cremation taken care of at the end of the study.

“I was informed what needed to be done and why and the reason that it needed to be done quickly (...) I managed to do what needed to be done in the length of time that was dictated before I allowed myself to grieve”—LG-01-NOK (Spouse) Part II

“[W]e knew that the body was going to be taken fairly quickly and that it was required quickly in order to process the study and so we were well-informed about that and [um] I understood that”—LG-05-NOK (Sister) Part II

“Last Gift was taking care of the cremation so I didn’t have to worry about that either”—LG-08-NOK (Close Friend) Part II

In sum, the Last Gift study embodied several aspects of conducting research at the EOL, including paying attention to the emotional context and bereavement issues. NOK identified possible ways to help ensure study success, such as early involvement and inclusion of NOK, clear communication and information, and attention to the logistical issues surrounding body donation.

Discussion

Overall, the Last Gift study left a positive imprint on NOK, and postmortem tissue donations were highly acceptable in our small sample of NOK. Our thematic analysis revealed five key themes: (1) NOK viewed the Last Gift program in a positive light and had an accurate overall understanding of the study; (2) NOK identified factors motivating participants to donate their body to science, including positive personality traits, the desire to serve a higher purpose, and altruism; (3) NOK identified benefits of the Last Gift study for both the donors and themselves; (4) NOK did not perceive any physical risks or decisional regrets of the study but wanted to minimize psychosocial impacts and ensure the dignity of participants at all times; and (5) while participating in the Last Gift study was an overall positive experience, NOK noted elements that remained essential to the successful implementation of EOL HIV cure-related research (e.g., early involvement and inclusion of NOK, clear communication and information, professionalism, and attention to bereavement and logistical issues related to the body donation).

Our study uniquely contributes to increased understanding and knowledge of what is important, from the point of view of NOK, to ensure successful implementation of HIV cure-related research in the EOL context. Given the novelty of EOL translational HIV cure-related research and the crucial role played by NOK in carrying out Last Gift participants’ wishes, our findings shed light into the psychosocial and practical dimensions of NOK participation. Our qualitative study further advances the socio-behavioral science literature on HIV cure-related research by examining perspectives of NOK. To the best of our knowledge, this is the first time socio-behavioral scientists have explored perspectives of NOK in the context of HIV cure-related research.

Importantly, we are encouraged to find out that NOK were left with a positive impression and generally accurate understanding of the Last Gift study. Their overall acceptance of the Last Gift study facilitated discussions around EOL and postmortem tissue donations. NOK viewed the study as providing gratification, fulfillment, and meaning to the participants, helping them make sense of a lifetime with HIV while constructing a significance for their death. This finding is consistent with a U.S. national survey conducted by

Steinhauser *et al.* on factors considered important at EOL,¹⁰ who found that patients and families viewed the dying process in broad psychosocial, existential, and spiritual terms, shaped by a lifetime of experiences, and centered on achieving a sense of completion or closure.¹⁰ Similarly, Goodkin *et al.* discussed how the search for meaning remains integral to the dying process.¹¹ Choosing to join the Last Gift study was life-affirming for study participants and their NOK, who placed value on a lifetime with illness and novel scientific contributions. Importantly, NOK understood that the study involved a full body donation at the time of death and that the study would not result in cure for HIV or the terminal illness.

The Last Gift study shows that participation in EOL HIV cure-related research is associated with positive participant personality traits, the desire to serve a higher purpose, and a deep sense of altruism. In theoretical discussions of altruism in terminal cancer patients and rapid tissue donation programs, Quinn *et al.* defined altruism as “selfless sacrifice or gesture made to benefit humanity in some way without the expectation of a direct benefit in return.”¹² The authors distinguished between three types of altruism relevant in the context of postmortem tissue donations: (1) gifting relationship (full body donation), (2) reciprocal altruism (involving elements of expected returns for the donor and the NOK, including psychosocial support), and (3) empathy-induced altruism (conferring a sense of community and loyalty to a group).¹² Similarly, our NOK interview data showed that altruism was aimed at advancing science, contributing to the HIV community, and helping others in death. Our study strengthens findings of previous socio-behavioral research showing that PLWHA are deeply motivated by altruism, solidarity, and activism to advance HIV cure-related science.^{7,13–16} The concept of “biological citizenship” holds particular salience in the Last Gift study setting.¹⁷ Participants (and sometimes NOK) view themselves as belonging to a specific biological group (living with HIV) and desire to contribute toward scientific progress for this particular group. In fact, Last Gift participants survived a disease that was once untreatable,¹⁸ and some even spent their lives advocating for improved treatment options.⁵ EOL HIV cure-related research may represent a new frontier in how PLWHA and their NOK are organizing themselves around research, helping shape the trajectory of a new science.

The Last Gift study also showed that perceived benefits, such as feeling valued, having peace of mind, hope, feeling in control, and emotional support at the EOL are critical to participation. While there was no expectation of medical benefits, the emotional and psychological aspects of Last Gift study participation cannot be discounted. NOK viewed the participants’ decision to donate their body to science as inherently emotional and psychosocial. Similarly, previous socio-behavioral research has placed emphasis on the emotional benefits of HIV cure-related research participation, such as increased positive outlook, enriched self-image, hope, self-reflection, and support.¹⁹ Similar accounts dominate the kidney and organ donation literature.^{20,21} Importantly, the Last Gift study gave control to participants over how they would ultimately serve their community and what their final contribution to humanity would be. This sense of control and self-determination, associated with autonomy, is a factor considered important at the EOL for both patients and

TABLE 2. SUMMARY OF FINDINGS FROM IN-DEPTH INTERVIEWS WITH NEXT-OF-KIN AND IMPLICATIONS FOR END-OF-LIFE HIV CURE-RELATED RESEARCH

<i>Summary of findings</i>	<i>Implications for EOL HIV cure-related research</i>
<p>NOKs perceptions and understanding of the Last Gift study</p> <p>Perceptions of the Last Gift study among NOK were overwhelmingly positive. This translated into support for the Last Gift participants' decision and feelings of pride and honor.</p> <p>NOK understood the general understanding of the study, including the full body donation to investigate HIV reservoirs in deep tissues, and the fact that the study would not lead to cure for HIV or the terminal illness as an expected outcome.</p>	<p>Teams involved in EOL HIV cure-related research should assess perspectives and understanding of NOK as critical stakeholders in the research effort.</p> <p>For full body donations to go forward, NOK must accept the decision of the participants and be willing to let go of the body of the deceased at the EOL.</p> <p>Both Last Gift participants and NOK should have a clear understanding that the research program will not lead to cure for HIV or the terminal illness.</p>
<p>Perceived motivators for Last Gift participants</p> <p>NOK identified various possible motivators for joining the Last Gift study on the participants' part, including positive personality traits, the desire to serve a higher purpose, and deep sense of altruism—including scientific altruism, HIV-specific altruism, and altruism in death.</p>	<p>Participation in EOL HIV cure-related research should be clearly recognized as motivated by the donors' and NOKs deep sense of altruism.⁷</p>
<p>Perceived benefits of the Last Gift study</p> <p>Perceived benefits for donors included feeling valued, peace of mind, control at the EOL, hope, and support throughout the dying process.</p> <p>Perceived benefits for NOK included the satisfaction of helping Last Gift participants fulfill their dying wish, and being able to contribute to the research program.</p>	<p>The psychosocial needs of EOL HIV cure-related research should be appreciated for both participants and their NOK. The research design must remain sensitive to the needs of terminally ill individuals and their NOK.²²</p> <p>Empirical research should attempt to understand psychosocial benefits of HIV cure-related research participation, for both participants and NOK, to protect their well-being throughout the study.</p>
<p>Perceived concerns of the Last Gift study</p> <p>NOK perceived minimal concerns related to the Last Gift study, centered around minimizing emotional and psychosocial impact, ensuring comfort and dignity of participants, and maintaining privacy and respect.</p> <p>NOK did not report major decisional regrets, only that the participants could not witness their unique contribution to science.</p>	<p>EOL HIV cure-related research teams should make every attempt to minimize the emotional burden and death-related distress associated with the program.</p> <p>Dignity of Last Gift participants and their bodies must remain paramount to prevent emotional distress, preserve trust in the research enterprise, and show respect for NOK.</p> <p>EOL HIV cure-related research teams should remain alert to possible concerns and complications to constantly improve the program for both participants and their NOK.</p>
<p>EOL HIV cure-related research implementation issues</p> <p>The Last Gift study embodied several aspects of implementing research at the EOL, such as paying attention to the emotional context and bereavement issues.</p> <p>NOK identified ways to facilitate study success, such as their early involvement/inclusion of NOK, clear communication and information, and clarity around logistical issues surrounding the body donation.</p>	<p>EOL HIV cure-related research teams must ensure early involvement and clear communication with NOK to clarify their roles in the study and minimize conflicts during the study and at the time of death.</p> <p>Informational needs of NOK can be fulfilled in multiple and creative ways, including brochure about the program.</p> <p>The definition of NOK should remain broad for people living with HIV/AIDS who may have untraditional arrangements.</p> <p>EOL HIV cure-related research teams should go beyond minimizing concerns to actively supporting NOK during the dying process and bereavement, including emotional care, even through this may blur the boundary between research and care. In addition, the Last Gift team must reinforce the message that the program involves a clinical study that does not influence palliative or hospice care.</p> <p>Logistical details around the body donation should be clearly communicated with NOK. Research teams should ensure the body donation remains as respectful as possible.</p> <p>Cremation should be seen as a necessity and not as a benefit of the study.</p>

EOL, end of life.

families and was found to correlate with quality of life and a “good death.”^{10,22}

Because EOL HIV cure-related research occurs as participants and their NOK prepare for death,¹¹ the study team must remain sensitive to the psychosocial needs of study participants while minimizing emotional burdens and death-related distress.²³ Interestingly, NOK also reported benefiting from the study by helping participants fulfill their last wishes and contributing to science. To the best of our knowledge, this is the first time NOK have weighed in on perceived benefits and risks of HIV cure-related research participation. While the Last Gift study informed consent documents clearly stated there would be no expected benefits of joining the study, it is clear that both participants and their NOK benefited emotionally and psychologically. A similar contradiction has been witnessed in the context of HIV cure-related research conducted in Thailand.^{13,24} Importantly, our research extends the discussion of inclusion benefits to NOK²⁵ and contributes to an important discussion around benefits (and risks) experienced by third parties in HIV cure-related research.²⁶

Narratives focused on minimizing emotional and psychosocial impact, ensuring comfort of participants, and maintaining dignity and respect. Based on our review of ethical considerations for HIV cure-related research at the EOL, we believe patient/participant centeredness must remain a core principle of study implementation.^{5,10,22} Ethical guidelines for research with the recently dead have emphasized dignity of participants at all stages of research.⁸ Deceased individuals should be treated with the same respect and dignity as the once-living donor.⁸ The rationale for such an approach is threefold: (1) it prevents emotional distress among the living, including NOK, (2) it preserves trust in the research enterprise, and (3) it shows respect for the surviving NOK who have a deep connection with the donor.^{8,27} Thankfully, the NOK in our study did not report major decisional regrets to being part of the study. We will remain alert as to possible concerns of NOK to keep improving the study for everyone involved.

The study also embodied several aspects of conducting research at the EOL,^{11,23,28–30} and NOK provided insight into how to improve the design of EOL HIV cure-related research. As revealed in our study, and similar rapid research autopsy programs in oncology,³¹ it is imperative to involve NOK as early as possible and engage them as true partners in the research endeavor. To date, we have not experienced objection from NOK around body donations. NOK have not expressed concerns about being unable to spend time with the body of the deceased after death. Moving forward, it will be critical to ensure clear communication and expectations with NOK throughout the study to clarify their role and minimize concerns during the research and at the time of death.⁵ Clear communication represents a recurrent theme in the EOL care literature to prevent conflicts and build trust with NOK^{27,30,32,33}; however, we acknowledge that some Last Gift participants may not want to engage NOK early in the process.

Ideally, the research team should go beyond minimizing concerns of NOK, and actively provide support, despite the necessary demarcation between clinical research and care.⁵ Our study showed the importance of paying attention to the emotional context and bereavement issues in the

EOL context. It is noteworthy that NOK perceived psychosocial benefits to being engaged in the Last Gift study, blurring the boundary between research and care. Consistent with the EOL literature, NOK have a distinct need for empathy and support, and also expect their loss to be acknowledged.^{30,34–36} Beyond psychosocial and emotional support, we found that NOK appreciated the personalized approach and the attention to practical and logistical issues throughout the study. In particular, NOK valued that cremation would be covered following the rapid research autopsy. The cremation, however, should not be construed as a benefit of the program, but a necessity given the invasive nature of postmortem research procedures.⁵

We acknowledge a number of limitations in our study. First, given the timing of the IRB approval for the NOK socio-behavioral research component, we were unable to conduct the Part I interview with LG-01’s NOK (Spouse), and two of the LG participants (LG-02 and LG-06) did not refer an NOK. Second, it is possible that Last Gift participants referred supportive NOK leading to selection bias. Future research should study reluctant, opposing or non-facilitating NOK to better understand their views and how this may affect study implementation. It is also possible that NOK underreported negative aspects of the Last Gift study, leading to social desirability bias. Third, some of the interviews were emotional due to discussions around the EOL process, and our interviewer (S.C.-G.) made every attempt to minimize emotional upset or death-related distress and none of the interviews were terminated early as a result. We did not delve into manifestations of bereavement for NOK—physical, emotional, or psychological.³⁷ Fourth, our study was conducted with a small number of participants at one clinical research site and is thus not generalizable. Similar EOL HIV cure-related research efforts are emerging throughout the United States, Canada,^{2,7} and Europe, and we hope additional and more diverse perspectives of NOK will soon be added to the literature. These limitations notwithstanding, the use of in-depth interviews in a safe setting yielded rich data on a very sensitive topic. Our findings are helpful in informing efforts to improve the Last Gift study, and similar EOL translational research programs in the future.

Table 2 summarizes the key findings from our interviews with NOK and possible implications for EOL HIV cure-related research.

Conclusion

In conclusion, our qualitative study uncovered the perspectives of supportive NOK as part of the Last Gift rapid research autopsy program at the UCSD. Future research will need to better understand perspectives of NOK who may be reluctant to the program and incorporate considerations for how motivated Last Gift participants will need to overcome barriers to participation from opposing NOK. Our findings challenged the belief that NOK are outside the scope of the research program. In highly innovative and potentially controversial EOL HIV cure-related research, research teams must interact with both participants and their NOK as true partners and collaborators. As illustrated in NOK accounts in our study, one can only appreciate the true partnership, reciprocal trust, and respect that developed between the Last Gift research team, study participants, and their NOK. Our

results emphasize the importance of proactively engaging NOK and integrating socio-behavioral research methodologies to understand the effects of participation on all parties involved. Given the complex and multifaceted nature of EOL HIV cure-related research, we endorse a humanist approach and aim for an inclusive, compassionate, and ethical process.

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Appendix Table A1

APPENDIX TABLE A1. SUPPLEMENTARY QUOTES

<i>Themes</i>	<i>Quotes</i>	<i>Interviews</i>
NOKs perceptions and understanding of the Last Gift study		
Support for Last Gift participant’s decision	“[T]hat’s something he wants so ... and if there’s any way of gathering knowledge from him doing this that’s great, so I’m very much for it”	LG-04-NOK Part I
	“I am completely [uh] supportive of his whatever decision he wants to make about his [um] future (...) he asked if I would support that and I said I would support anything he wanted to do”	LG-05-NOK Part I
	“I reacted as an accepting family member of his decision making”	LG-05-NOK Part I
Understanding of the study by NOK	“To study where the virus hides in the body to provide better treatment and a cure for HIV”	LG-03-NOK Part I
	“[T]o better understand where the reservoirs are allowing the virus to stay dormant”	LG-03-NOK Part I
	“Um, I think the primary purpose is to research you know the organs of the disease to see if they can learn anything to help others in the future”	LG-04-NOK Part I
	“To study the virus in various parts of the body and [um] and see how it affects the various parts of the body”	LG-05-NOK Part I
	“[I]t’s about understanding the progression of HIV in the body”	LG-08-NOK Part I
Perceived motivators for Last Gift participants		
Personality traits of Last Gift participants (e.g., generosity)	“[H]e’s always been very conscious about helping others and I think that’s his goal for the end of his life too, to help somebody somehow”	LG-04-NOK Part I
	“He always as long as I’ve known him was always helping somebody someway somehow”	LG-04-NOK Part II
	“He was very brave and being very open to everyone that would listen to him about the end of life”	LG-05-NOK Part II
	“[H]e was a very giving person. Just uh he cared about people and was always willing to give somebody a helping hand”	LG-07-NOK-I Part I

(Appendix continued →)

APPENDIX TABLE A1. (CONTINUED)

<i>Themes</i>	<i>Quotes</i>	<i>Interviews</i>
Serving higher purpose and existentialism	“[P]eople go through life wondering what it is God’s plan for us you know why we’re on Earth and what it is that we can do to provide help and knowledge to others and this project gave [Last Gift participant] that opportunity and he was very excited about it”	LG-01-NOK Part I
	“Creating meaning and feeling that you know in his becoming HIV positive that he will help others (...) to understand the disease better by donating his body”	LG-08-NOK Part I
	“A sense of purpose you know and um rationalizing why he’s dying so early in life that he could somehow contribute to the lack of years that he will be living in some beneficial way to others”	LG-08-NOK Part I
	“I feel that he wanted to feel that his existence served a higher purpose”	LG-08-NOK Part I
Scientific altruism	“I think that’s a personal gift and benefit to think that you know you’re helping somebody somehow somehow”	LG-04-NOK Part I
	“I think that he would like the research to help other people because it’s getting too late to help him”	LG-07-NOK-II Part I
	“[I]t would help hundreds of people, thousands of people to have this research done using him as a help you know”	LG-07-NOK-II Part I
	“I believe that [Last Gift participant] was given an opportunity to give back to the community and to the world, the details about how HIV (...) affected him and how it might affect others and how there might be a cure for it”	LG-01 NOK Part II
HIV-specific altruism	“[H]e just, he’s very conscious about trying to find a cure so that nobody has to go through what he has (...) and all the other problems with the organs from the medicine he’s taken all these years”	LG-04-NOK Part I
	“Um, he’s always been an advocate for research um and especially with the HIV um disease so I know he’s given money in the past for research and different community things so that’s why”	LG-04-NOK Part I
	“[T]his is something that [Last Gift participant] wanted to do as his final contribution to our community”	LG-04-NOK-Part II
	“I think it’s to help others with the same thing that he has and so people live a better life from then on”	LG-07-NOK-II Part I
Altruism in death	“Um a way of giving back you know so that others can benefit from the experience that he’s had with HIV”	LG-08-NOK Part I
	“It means that through all the years that I’ve known him, through all the years that other people have known him, that there is a part of him that is still going on and still helping people and still providing information”	LG-01-NOK Part II
	“Well he was very gung-ho about this and he wanted to help others if he could even in death”	LG-04-NOK Part II
	“[E]ven though I knew he was gone, I knew that his whole life he always wanted to help people and he was still helping people after he was gone and that’s just I think the best way to go, to know that you’re trying to help others still even though you’re gone”	LG-04-NOK Part II
	“Well he has another terminal illness and so he was offered this and thought it would contribute to research and he wants to feel productive”	LG-05-NOK Part I
	“Despite having that early diagnosis in his short life, [Last Gift participant] felt that at least his body would [um,] have value in providing important information for other people (...) after he left the earth, they could study his tissue and learn more about HIV”	LG-08-NOK Part II
Perceived benefits of the Last Gift study		
Feeling valued at the EOL (participants)	“[E]verybody was there for him and definitely he did feel valued”	LG-03-NOK Part II
	“They were very kind and I feel that it gave him a sense of worth”	LG-08-NOK Part II
	“That he had control over [um] his [um] end and he could make it as peaceful as he wanted it to be”	LG-05-NOK Part II
Control at the EOL (participants)	“He had a lot of comfort um knowing that he had control over his end”	LG-05-NOK Part II
	“I see him as being proactive about his disease processes and about the end of life and sharing it with people”	LG-05-NOK Part II

(Appendix continued →)

APPENDIX TABLE A1. (CONTINUED)

<i>Themes</i>	<i>Quotes</i>	<i>Interviews</i>
Hope for scientific advancement (participants)	<p>“[H]ope that it will eventually lead to a cure to HIV in the future”</p> <p>“That way others that have AIDS are going to benefit from the study that they’re going to be doing”</p> <p>“I hope that his participation is good and solid and they find something in him that they can help others with”</p> <p>“Definitely to better understand HIV with the effects that HIV has on someone’s body long-term”</p>	<p>LG-03-NOK Part II</p> <p>LG-07-NOK-I Part I</p> <p>LG-07-NOK-II Part I</p> <p>LG-08-NOK Part I</p>
Support at the EOL (participants)	<p>“I think they were very cognizant of his needs during the entire journey”</p> <p>“He felt emotionally supported along the way and he knew that once his journey was done, that his body would still provide a legacy of information to help people understand HIV better”</p>	<p>LG-03-NOK Part II</p> <p>LG-08-NOK Part II</p>
Satisfaction of helping participants fulfill last wishes (NOK)	<p>“I just felt it was the thing that I could do for my best friend at the end of his life”</p>	<p>LG-04-NOK Part II</p>
Helping advance HIV cure-related science (NOK)	<p>“The positives to me were that in the medical field people do care about HIV and other diseases”</p> <p>“Contribution to research is a positive benefit”</p>	<p>LG-01-NOK Part II</p> <p>LG-03-NOK Part I</p>
Perceived concerns of the Dignity of Last Gift participants	<p>Last Gift study</p> <p>“He was able to ... when he realized that he was declining in his [uh] condition, he was able to select a time that he could leave and still have dignity and not be any more burdened with his disease process”</p> <p>“He told us that he was tired with the disease process that was progressing. It scared him, because he had a lot of difficulties, specifically breathing, moving, comfort, communicating and the Last Gift allowed him to be released from that in a dignified, comfortable manner, and that he was comfortable with”</p>	<p>LG-05-NOK Part II</p> <p>LG-05-NOK Part II</p>
Minimal concerns for NOK	<p>“With my personal views on life and death, and [Last Gift participant]’s views on life and death, I don’t see anything that could be construed that way. There could be others that have deeper religious convictions that might have viewed the autopsy as something not normal but as part as [Last Gift participant] and I were concerned it was a pleasure to be able to do and serve and provide what we were asked to do for the study”</p>	<p>LG-01-NOK Part II</p>
Minimizing discomfort at the EOL	<p>“I guess just know that uh being reassured that [Last Gift participant]’s wishes were uh addressed”</p> <p>“The fact that he was so weak at the end I know it was hard for you (...) that was the only negative”</p> <p>“The only concern was sometimes during the process [Last Gift participant] was very anemic and low on blood and he was very concerned about you know getting poked again, get his blood drawn, but everybody was always very cognitive of his concerns and adapted their schedule to when [Last Gift participant] felt better and more up to have more tests drawn”</p> <p>“Too much risk I would say if it impeded his well-being or his palliative care you know”</p>	<p>LG-05-NOK Part I</p> <p>LG-04-NOK Part I</p> <p>LG-03-NOK Part II</p> <p>LG-08-NOK Part I</p>
No decisional regrets	<p>“I have no regrets, no, and I would do it again if I could”</p> <p>“I do not regret that he participated at all it was a golden opportunity for him and he took it and he gave his all for it and that’s commendable and I’m so happy that he did it”</p> <p>“Not at all”</p> <p>“Nope, no regrets (...) I didn’t have any regrets because I knew it was something he wanted to do”</p> <p>“I don’t have any regret, because he was comfortable with his decision and he was dignified and peaceful”</p>	<p>LG-01-NOK Part II</p> <p>LG-01-NOK Part II</p> <p>LG-03-NOK Part II</p> <p>LG-04-NOK Part II</p> <p>LG-05-NOK Part II</p>
EOL HIV cure-related research implementation issues	<p>Personalized and reciprocal approach</p> <p>“You know it’s always very difficult [uh] dealing with end of life issues but [um] he felt that this was an important way to him to contribute to finding the cure for HIV so the overall experience (...) was emotional but it was [uh] very positive”</p>	<p>LG-03-NOK Part II</p>

(Appendix continued →)

APPENDIX TABLE A1. (CONTINUED)

<i>Themes</i>	<i>Quotes</i>	<i>Interviews</i>
Early involvement and inclusion of NOK	“I would have liked to [have] been involved in the study from the beginning”	LG-03-NOK Part II
	“I did feel included um I did not feel like a fly on the wall or somebody that was pushed back when everyone was talking to [Last Gift participant]. My feelings were taken into consideration, my emotions were taken into consideration and I was included in all discussions that [Last Gift participant] had”	LG-01-NOK Part II
Clear communication and information with NOK	“Everything that I expected the study to do has done it and without going into details because the details really weren’t that much because it was so cut and dry and we knew what to expect to happen. It did happen and I have been kept informed since then of any research developments that might have come up from the use of [Last Gift participant]’s tissues”	LG-01-NOK Part II
	“I didn’t expect him to go so quickly but I do know that he and I talked about it daily and what it was that he needed to do and I needed to do and what we needed to do together”	LG-01-NOK Part II
	“I would be kept informed of any change or updates to what is being done and especially at his end that he remains comfortable”	LG-05-NOK Part I
	“When he would have questions, they were answered in a timely fashion”	LG-05-NOK Part II
Emotional support for NOK	“They were there, they were supportive, but they withdrew to allow myself the personal time and space that I needed to grieve”	LG-01-NOK Part II
	“[T]hey were all very supportive (...) calling to make sure I was okay”	LG-03-NOK Part II
	“Extremely supportive, personal [um] comforting, really great communication throughout. I would say very valuable as a caregiver. I mean the intermittent texts to make sure that I was okay were priceless”	LG-08-NOK Part II
	“I had a support system of people that I could call as [Last Gift participant] was getting worse and that answered questions about dying and death, about cancer. [Um] I had a hotline that I could call 24 hours a day”	LG-08-NOK Part II
	“Lots of emotional support as a caregiver and constantly checking in to see how I was doing”	LG-08-NOK Part II
	“By staying in touch after [Last Gift participant] passed, making sure I was okay”	LG-08-NOK Part II
	“I mean, you were available every day, 24 hours a day”	LG-08-NOK Part II
	“[Y]ou provided me with a lifeline throughout so that I had somebody, so it was very valuable to me”	LG-08-NOK Part II
Professionalism	“There were no negatives. The program was very well done, very well thought up, the people that were involved in it were all friendly, they were all sincere, they were all professionals so do there were no negatives from me”	LG-01-NOK Part II
	“[T]here were no surprises. Everything was done very professionally and caringly”	LG-03-NOK Part II
	“The people that came at the end to retrieve [Last Gift participant], to bring him over for the autopsy, they were all very caring, professional—it was very you know under the circumstances it was done this experience was you know... definitely they were very attuned to what was going on”	LG-03-NOK Part II
Logistical aspects of body donation	“[T]he group was very good at following the procedures they had laid out as to what would happen”	LG-01-NOK Part II
	“I believe that the group covered all bases and thought about all issues”	LG-01-NOK Part II
	“[W]e knew that everything timewise was met and he was on his way hopefully to help someone”	LG-04-NOK Part II
	“[M]ake sure that at the end of his life that the Last Gift [team] would be notified of where he was at all times whether that as his apartment or at hospice”	LG-08-NOK Part II

EOL, end of life; LG, Last Gift; NOK, next-of-kin.