AIDS RESEARCH AND HUMAN RETROVIRUSES
Volume 35, Number 7, 2019
DOI: 10.1089/aid.2019.0021

Acceptability of Cell and Gene Therapy for Curing HIV Infection Among People Living with HIV in the Northwestern United States: A Qualitative Study

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Abstract

Multiple strategies to cure HIV infection are under investigation, including cell and gene therapy (C&GT) approaches. Research, and ultimately treatment, with these novel strategies will require patients' willingness to participate. To elicit the perspectives of people living with HIV specific to these novel approaches, we conducted 4 focus group discussions with a diverse group of 19 English-speaking men and women living with HIV in care at a large academic HIV clinic in the northwestern United States. Thematic analysis indicated participants expressed initial fear about C&GT research. They articulated specific concerns about risks, including analytical treatment interruptions, and thought only a person in desperate straits would participate. They voiced significant mistrust of research in general and believed there was already a cure from HIV that was being withheld from the poor. Overall, they were satisfied with their health and quality of life on antiretroviral therapy. These findings suggest the importance of community engagement and educational efforts about C&GT for HIV cure to ensure optimal collaborative partnerships.

Keywords: cell and gene therapy, HIV cure research, acceptability, sociobehavioral sciences, qualitative research, HIV/AIDS, people living with HIV

Introduction

Combination antiretroviral therapy (ART) is remarkably effective at suppressing HIV viral replication and preventing sexual transmission of HIV.[1] ART alone, however, will not cure HIV nor lead to elimination of latent HIV reservoirs. Strategies to cure HIV or control HIV in the absence of therapy are being investigated in the United States and around the world.[2] One such strategy involves cell and gene therapy (C&GT). Advances in C&GT have been driven in part by recent progress in non-HIV disease areas, notably inherited immune diseases and oncology.[3,4] Most C&GT approaches in the field of HIV cure research are aimed at making cells resistant to HIV infection or enhancing the immune system's capacity to clear HIV-infected cells. Examples include zinc finger nucleases, transcription activator-like effector nucleases (TALENs), clustered regularly interspaced short palindromic repeats (CRISPR)-Cas9, antibody gene transfer, engineered T cells, and chimeric antigen receptor (CAR) T cells.[5,6] At present, most C&GT strategies toward an HIV cure remain in the preclinical stage of development, but some have entered human testing. Such studies require the altruistic participation of people living with HIV (PLWH),[2] as those participating will not benefit directly from the testing and, indeed, may risk adverse effects.

Community perspectives regarding C&GT for curing diseases can be positively influenced by successful outcomes, such as the case of Timothy Ray Brown, the first person cured of HIV infection.[7] This individual received a hematopoietic stem cell transplant from a donor homozygous for the C-C chemokine receptor type 5 (CCR5)-Δ32 gene deletion, following a diagnosis of acute myeloid leukemia. (This rare but naturally occurring mutation makes cells resistant to common strains of HIV.) A second person in London was found to have a sustained HIV-1 remission following a similar

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hematopoietic stem cell transplant.[8] Furthermore, public attitudes can also be favorably influenced by technological developments in other fields, such as the recent commercial approval of CAR T cells for the treatment of leukemia and lymphoma.[9] Community perspectives can also be tarnished by setbacks, such as recent deaths in cancer immunotherapy trials,[10] the death of Jesse Helsinger during a Phase 1 gene therapy trial in 1999,[11] or international public outcries like those caused by the recent announcement of the use of CRISPR technology to make Chinese embryos resistant to HIV infection through CCR5 gene deletion.[12,13]

Perspectives of African Americans and minority groups are particularly important to consider as they bear a disproportionate burden of HIV in the United States.[14] Moreover, they have been subject to a history of discriminatory treatment at the hands of medical researchers, with perhaps the most egregious example being the Tuskegee syphilis study in which African American men with syphilis were denied available treatment so that researchers could observe the natural history of the infection.[15] Indeed, research consistently demonstrates as many as one third of African Americans surveyed believe that HIV was deliberately introduced by the U.S. government to decimate the African American community.[16]

There has been limited exploration of public and community perceptions around C&GT to cure HIV infection among any group. While there is an emergent literature on the acceptability of various HIV cure research modalities in general, both in the United States and abroad,[17–22] acceptability data remain scant about C&GT for HIV cure in particular. Biomedical researchers need to consider the preferences and perspectives of PLWH to effectively recruit and retain participants in clinical trials of C&GT.[23] Toward this end, and in line with similar acceptability research of C&GT in non-HIV fields,[24–28] we conducted a formative focus group discussion (FGD) study with PLWH in the Seattle, Washington area.

Methods

FGDs were conducted in December of 2017 in close collaboration with defeatHIV Community Advisory Board members. We chose FGD because attitudes, feelings, and beliefs can often be more easily revealed through interaction among group members.[29] FGDs are also helpful at gauging community-level understanding and assessing how participants ascribe meanings to various concepts.[29,30] The study objective was to inform community engagement and recruitment practices for upcoming C&GT trials in the Seattle, Washington area as part of the work of the Delaney Cell and Genome Engineering Initiative (defeatHIV),[31] a consortium of researchers advancing C&GT for curing HIV infection. All FGD participants were recruited with purposive sampling from the Madison Clinic, the largest academic HIV primary care clinic in the northwestern U.S. Participants were recruited by research personnel who briefly presented the study and assigned interested individuals to specific groups based on time availability and prespecified criteria. We aimed to oversample African Americans because they have been underrepresented in research. Based on our initial community engagement efforts, we noticed that some groups may have had limited prior exposure to C&GT concepts and held doubts about HIV research based on conspiracy theories. We also oversampled men who have sex with men because they represent the majority of PLWH in the Seattle, Washington area. We attempted to create fairly homogenous groups because we believed this would facilitate frank discussions. Eligibility individuals were at least 18 years old, English speaking, living with HIV, and able to provide written informed consent.

All FGDs were conducted in English in a private conference room by a trained behavioral scientist (J.S.) not involved in the care of participants. Individuals first completed a brief questionnaire eliciting data on sociodemographic information, HIV treatment variables, and experience with prior research. A research assistant (Z.M.) took detailed notes during each focus group (FG). FGDs were audiorecorded and lasted between 60 and 90 min. All participants provided written informed consent and received a $35 gift card and transportation reimbursement for participating. The University of Washington Institutional Review Board (IRB) approved the study.

The FGD facilitator followed a discussion guide, developed after a literature review and consultations with the defeatHIV Community Advisory Board and biomedical researchers involved in C&GT research for HIV cure (Supplementary Data S1). After inquiring about participants' prior research experience, the facilitator asked whether they had ever heard of C&GT. Next, the facilitator read this description of C&GT: ''Gene/cell therapies can involve taking cells out of the body, modifying the genes to make them resistant to HIV infection or better at recognizing and targeting HIV, and then reinfusing them into a person. Some strategies involve delivering special gene-cutting molecules into the body that can snip out HIV genetic material that has become integrated into human cells.'' She then asked about participants' initial reactions, concerns, and understanding of potential risks and benefits of C&GT—both to themselves and society. Participants were asked what they would need to know about the study procedures to be willing to undertake them and what precautions would make them feel safe doing so. The facilitator also asked specifically about perceptions of analytical treatment interruptions. Finally, she asked about the best ways to reach people in their communities about C&GT and what community members might need to become interested in participating in C&GT clinical studies.[32]

All FGD were transcribed verbatim (with personal identifiers redacted), with verification against audio files. We used content analysis, combined with a social constructivist approach to grounded theory (to assess how participants construct meaning and knowledge) and phenomenology (to capture the essence of a phenomenon and the lived experiences of individuals) as our methodological approaches.[30] After undergoing an extensive assimilation process, transcripts were analyzed using both *a priori* and data-driven, emergent codes. The codebook contained a code name, brief description, and a coding example. A social scientist (K.D.) applied the codes to the data, with a second coding by a research assistant (S.L.). We used an open coding method, where we identified salient text units, ascribed codes, and categorized and organized the codes in a continuous and iterative process.[33] Discrepancies were resolved through discussion. We used MAXQDA, VERBI GmbH (version 12.1.3, Berlin, Germany) to support analysis and data management.

Results

Nineteen participants (age 33–66 years) took part in four FGs: Black/African American men ($n=6$), Black/African American women ($n=4$), women of diverse racial/ethnic backgrounds ($n=6$)—including 1 male-to-female transgender person, and Black/African American men who have sex with men ($n=3$). Additional demographic information can be found in Table 1. All participants were treatment experienced and currently in HIV care and had previously participated in HIV-related research—either for social sciences and/or clinical studies.

Thematic analysis indicated participants expressed initial fear about C&GT research. They articulated specific concerns about risks, including analytical treatment interruptions, and thought only a person in desperate straits would participate. They voiced significant mistrust of research in general and believed there already was a cure from HIV that was being withheld from the poor. Overall, they were satisfied with their health and quality of life on ART.

Table 1. Characteristics of Focus Group Participants

Focus group member characteristics	*1*	*2*	*3*	*4*	*Total (%)*
N					
Gender					
Male	6	0	0	3	9 (47.4)
Female	0	4	5	0	9 (47.4)
Transgender (male to female)	0	0	1	0	1 (5.3)
Age (years)					
18–29	0	0	0	0	—
30–39	1	0	0	1	2 (10.5)
40–49	1	1	4	0	6 (31.6)
50–59	1	2	0	0	3 (15.8)
60–69	3	1	2	2	8 (42.1)
Ethnicity					
Black or African American	5	4	4	3	16 (84.2)
White	0	0	1	0	1 (5.3)
Native Hawaiian or Other Pacific Islander	0	0	1	0	1 (5.3)
More than one of the above	1	0	0	0	1 (5.3)
Education					
Some high school (9–12 years)	1	1	4	0	6 (31.6)
High school graduate or GED	3	3	1	2	9 (47.4)
Associate degree or technical school training	2	0	1	1	4 (21.1)
Employment status					
Not working	6	4	5	3	18 (94.7)
Working full-time	0	0	1	0	1 (5.3)
Working part-time	0	0	0	0	—
Income					
$0–999 per month	4	4	4	3	15 (78.9)
$1,000–1,999 per month	2	0	1	0	3 (15.8)
$2,000 or more per month	0	0	1	0	1 (5.3)
Time since HIV diagnosis (years)					
<5 years	0	0	0	0	—
6–10 years	2	0	2	0	4 (21.1)
>10 years	4	4	4	3	15 (78.9)
Prior injection drug use					
No	5	3	4	2	14 (73.7)
Yes	1	1	2	1	5 (26.3)

GED, general education development/diploma.

Given the small number of groups and group membership, we did not conduct a comparative analysis of results across groups. Interestingly, we found significant overlap in themes and convergence in concerns about C&GT between FGs. Some themes were more strongly emphasized in specific FGs, and these may have been influenced by specific individuals in the group. For example, the first FG desired more research on the effects of combination antiretroviral therapy (cART), including long-term side effects on specific organs in the body. The second FG discussed the incurability of HIV and expressed general aversion to participating in C&GT research. Participants in the third FG noted doing very well on cART and living a normal life more than any of the other groups. Finally, the fourth group highlighted an aversion to gene modification and mistrust of government-funded clinical research.

Reactions to C&GT research

None of the participants had previously heard about C&GT as a strategy for curing HIV infection. After receiving a brief description of C&GT, most participants expressed fear: ''It's scary!'' (FG1), ''Frightening!'' (FG4), ''I'm afraid to change what's already in there'' (FG1), and ''It's going to change the human race if they start modifying genes'' (FG4). Most fears stemmed from the fact that something would be injected into them and that genes would be manipulated in the process.

Genes, you know uh, I got some pretty tough genes, they're pretty good, and I really would hate for you to muck around with my genes (FG1)

Ain't no way I'm letting somebody go in my body and change my genes and all that… I mean this! (FG4)

You got like 46 DNA things right yeah so like 23 and 23 right so if like, it's like, it's like she said you know, like with the stem cells and stuff, it's just things that you're not supposed to (…) mess with! (FG4)

Participants viewed gene modification as being invasive and expressed liking their bodies the way they are. They viewed C&GT as being a risky approach to curing HIV infection that could possibly lead to significant pain and side effects, or even death.

Yeah… see… I don't want to start something that's gonna kill me (FG1)

Investigator (I): What would be your biggest fear?
Participant (P): Dying (FG3)

I'm gone give you… these fake wings and I want you to jump off this cliff and we gonna see… we're gonna see… (FG1)

These fears led most FGD participants to be quite adamant about not wanting to participate in C&GT clinical research.

I'm actually going to sign my name on a paper for you to do this… no! (FG4)

I wouldn't [take a chance] (FG1)

Nope, I'm not trying nothing new (FG2)

I don't want to do it. Nah, I'm alright. I got my one pill, I got enough going on (FG2)

That's not going to work period I'm not even going to give it a thought in my brain. Don't even ask me (FG2)

That sounds amazing but I couldn't do that! (FG4)

I don't want nobody to put nothing in my body I don't know how it's going to take to it, I don't know how it's going to react to it, I'm cool like this (FG4)

One of the main reasons for refusing to participate in C&GT clinical research was not wanting to serve as a guinea pig or test subject. This theme was emphasized in all FGs.

And I don't know if I'm secure in feeling, to be the test dummy (FG1)

You know it's just that I don't want to be a guinea pig (FG4)

Some FGD participants expressed skepticism that C&GT could lead to a cure for HIV infection or protect the immune system against HIV. Most of the skepticism was tied to a belief that a cure for HIV was not an immediate medical possibility. This theme was particularly strong among African American/Black women (FG2).

No, we're stuck for the rest of our lives. Regardless of how we got it [HIV], we're stuck with it (FG2)

This is a lifetime commitment, for real (FG2)

They ain't ever going to find no cure (FG3)

African American/Black men (FG1), however, appeared more optimistic about the possibility of finding a cure for HIV infection.

I think they're getting close (FG1)

Just like cancer it's like a cell, they say they got cures for everything, you know (…) I think they're getting close to curing certain diseases and stuff, you know (FG1)

Satisfaction with current health status

Another reason dampening interests in C&GT was that participants reported that they had learned to live with HIV and were comfortable with their health status. Some of them even forgot that they had HIV at times. The majority were satisfied with their current HIV treatment and did not want to undertake risky interventions that would jeopardize the effectiveness of current treatment or undergo procedures that were inconsistent with the current standard of care. This theme was prominent in all four FGs.

Yeah, you know, the pills are keeping me healthy, you know (FG1)

You say to think positively (…) I do think positively about my disease. I'm positive. The way I think is positive I got it, I ain't going nowhere, and I got to live with it for the rest of my life. (FG2)

Well I know the one pill I'm taking ain't going to cure me neither but you know, you know I feel good (FG3)

Well like I take 2 pills a day you know what I'm saying so like taking 2 vitamins you know and it's just as simple as that, you know (FG4)

Participants in three of the FGs expressed the preference to leave some things alone.

But, if you can't find a real way to positively tell me this will work then I'm afraid to mess with it. Because what does it say, how's it go… if it's not broke, don't fix it (FG1)

You're always trying to… you're always trying to fix something that's not broke. Leave it alone! (FG2)

You have to leave some things alone… (FG4)

A minority of FGD participants would consider participating in such studies. The main reasons for being willing to participate included not having anything to lose, helping find scientific answers, monetary compensation, and, more rarely, wanting to assist others. Interest in C&GT increased if the approach would eliminate HIV completely.

You know, I would, I would, I would try the study cause look (…) I'm almost 65 years old so what [do] I got to lose (FG1)

I guess it's good to be part of something that's going to like give answers to something so I'd be interested (FG3)

Other participants said they would consider C&GT if they could see another person cured first. They did not want to be the first person in line to test new investigational cure strategies. FGD participants recommended that C&GT be tested on the researchers themselves or someone famous first—like Magic Johnson—because if they participated and died in the process, no one would know or would care. The majority of FGD participants expressed reluctance to take part in this type of research.

Although all FGD participants had previously taken part in HIV clinical or social sciences research, they required strict conditions to consider participation in C&GT clinical research. For example, some would participate in a clinical study if there was a guarantee that their health would improve. Others would decline participation if there was no personal benefit, if the protocol required specific procedures such as a spinal tap, or if there was too much blood drawn. One participant said:

If it's too much hassle either medically, either physically or mentally or whatever, then it's not worth it (FG3)

Some participants offered risk–benefit calculations when asked if they would participate in clinical research.

Possibly, it just depends on the side effects you know, what're the possible benefits (FG3)

It's a possibility I just got to weigh my options and see where I'm at (FG3)

I don't know I guess I'd have to like research more about side effects of like the medications that I would take and like the comparisons between doing the study for whatever and then doing or just taking my meds and just like what my situation in life is in the future so… (FG3)

Some thought those who were in desperate situations or who would have little to lose by participating would be good candidates for C&GT clinical studies.

I think if somebody really do that it would have to be somebody who's not undetectable (FG2)

I know some people who are in so much despair that if you gave them somewhere to live for a month probably, you know what I'm saying they would do it just because they got a house and (…) it's 'cause they got some dignity back (FG4)

Financial incentives were another important factor in participants' decision-making processes. FGD participants asked several questions about the amount of financial compensation that would be provided in exchange for participating in C&GT studies.

How much are you going to pay me? (FG1)

You got to get reimbursed and stuff. You're giving them your cells (…) what am I worth? If I'm giving something you want to get something (FG1)

Specific concerns and questions about risks of C&GT

FGD participants expressed concerns regarding the possible clinical risks of C&GT. They also asked several questions about

this investigational approach. A minority of participants worried about the risk of futility of C&GT research.

What if it doesn't work? (FG2)
It might not work, it might not be… And then all the side effects…(FG2)
If it would alter, like, I don't know about if it would alter my genes, no I mean what would it alter and what would be the effect you know? (FG3)
You don't know if it's going to heal me, if I'm going to have to take meds again or… (FG3)

Participants showed uneasiness about the irreversibility of C&GT.

You couldn't reverse it (FG1)
It's stuck with you whereas if you're just taking medication you know it's just gonna, you know you can always switch up, but with gene therapy you're stuck with it (FG1)
This is a long-lasting agent and it's in your body, you know I mean it's just gone continue to do what it's gonna do, you know (FG1)

Another concern related to the risks of early phase clinical research, and not knowing the possible undiscovered consequences of C&GT.

It's too early because, it's too early because uh, you don't know the repercussions of that yet (FG1)
It's pretty much new territory too and nobody really knows anything about it so we would be like the first batch of people ever (FG4)
They never do anything right the first time (FG4)

Relatedly, participants voiced strong concerns about the possible side effects of C&GT. They discussed wanting to live long, healthy lives, and any adverse reactions might interfere with their activities or spending time with loved ones. They expressed fears about possibly becoming paralyzed or incapacitated for the rest of their lives. Concerns about the clinical risks of C&GT were prominent across all four FGs.

Uh oh, uh oh, uh oh, and then you got to figure out how you messed that, how to clean up what you just messed up (FG1)
So, uh, uh, tests are fine, but I'm afraid it may shorten my life (FG1)
It might make you go quicker (FG2)
Because we don't know what will happen to us really (FG3)

African American women (FG3) voiced a strong preference for therapies affecting only somatic cells as opposed to germ line cells that could pass on genetic changes to subsequent generations.

Participant (P): You couldn't give that to your children would that matter to you?
P: Yeah
Interviewer (I): That would make it better?
P: Mhm
P: Yeah
P: Yeah then I can have sex and not worry about the kids (FG3)

FGD participants became anxious that C&GT might cause undesirable changes to their physical appearance, such as altering their sexuality or skin color, or growing another finger, a third eye, or breasts for men.

You know, so uh, and I don't want to look like no sasquatch monster either (FG1)
Am I gonna grow a sixth finger on my fingers (FG1)
It might alter it might damage (…) like eye color, hair color, personality (FG3)

Participants asked a multitude of questions about C&GT, particularly how it would affect their overall health or HIV status, including CD4 count and viral load, about testing new interventions in animals and humans, and about the possible outcomes of the C&GT interventions.

What does it mean if you already have an undetectable viral load? (FG1)
So, what are they focusing more on the CD4 count or the viral load? (FG3)
How can they control HIV without the meds? (FG3)
Where do they get the genes from? (FG4)
So how do they, um, test, other than human beings, how do they test these research, these pills, the studies that they're trying? (FG1)
So, how have they figured this stuff out? Have they used like live people… have they used rats or monkeys or something like that? (FG4)

Concerns about analytical treatment interruptions

Participants in all groups expressed concerns about analytical treatment interruptions. They appreciated their HIV medication, understood the importance of adherence in maintaining viral suppression, and were reluctant to risk their treatment success.

I look at it like right now, you know, I'm kind of being given a second chance at life you know and to stop that and to take a chance and, that would be a pretty… you know, I mean (FG1)
I'm committed to my 'tripla. I love it! (FG2)
I ain't even doing that! [analytical treatment interruption] (FG4)

When participants learned that some HIV cure-related studies warranted analytical treatment interruptions, they became even more averse to participating in research. Narratives focused on HIV possibly turning into AIDS and developing resistance to current antiretroviral regimen. Participants recounted previous negative experiences with stopping HIV medications and feeling the negative effects almost immediately. They also did not understand why they would be asked to interrupt medication when their HIV clinicians placed so much emphasis on ART adherence.

That's very risky. Very risky… (FG1)
I'm going to say it just like I said it (…) but what happens to these medications when we completely cut them off? You better be paying attention to the study real tight because if it's going too far north, that's taking a chance on a life that I'm already living (FG1)
Resistance, is resistance is resistance, you know what I'm saying (FG1)
So, if they stop you from taking it and it's not, that's what, you can continue developing HIV/AIDS (FG3)
Can I say something real quick? Now all the years that (…) my doctor, right… She always tells me you can't miss your medicine, you can't miss your medicine, you can't miss your medicine now you gone tell me these people think it's okay to miss your medicine 'cause they gone give you some medicine. Something wrong with that! (…) Yeah, all this time my doctor been telling me take your medicine, don't miss it, don't miss it, don't miss it, numerous doctors, from Seattle to Baltimore now

they've been telling me to take your medicine, take your medicine, and all of the sudden some doctors come along because they've found something inside a Petri dish that they want to mess with my medicine, and give me some different types of medicine… (FG4)

Further questions were raised about the duration and frequency of analytical treatment interruptions, the type of medical monitoring that would be offered, and compensation in case of research-related injuries. Given concerns about risks of C&GT research, particularly when combined with treatment interruptions, the majority of FG participants would prefer to stay on their current HIV medication regimen than undergo what they perceived to be substantial risks to their health.

Mistrust of government-funded clinical research and need for more information

An emergent theme was the prevalent mistrust in clinical research as well as conspiracy theories surrounding HIV. Several participants thought a cure for HIV was already in existence, hidden by insurance companies interested in making profits or only available to wealthy individuals and celebrities.

P: Man has created certain diseases okay, for every disease that's created there's a cure.
I: So you think for HIV there is a cure
P: There is a cure (…)
P: It's for people with lots of money…
P: People with money… How did Magic [Johnson] all of a sudden have it and then he didn't have it no more. Magic, come on now. He no longer has it. He no longer has it. (FG4)

References were made to previous unethical research, including the Tuskegee syphilis study and experiments where individuals were unknowingly injected with pathogens. A general mistrust of government-funded clinical research involving genes was expressed, particularly among African American men who have sex with men (FG4). Participants thought the government was purposely trying to get rid of specific groups, such as PLWH or drug addicts.

They don't care, they just doing the research you know they just want to cure things (FG4)
Well, it's just, I don't know I'm not a conspiracy theorist but I don't trust the government (…) you know like got our best interest in mind especially people that are drug addicts or having unprotected sex, people that would contract HIV I don't think they have our best interest in mind for the most part and I don't think that they're injecting us with different genetic makeup, it doesn't seem like it's trustworthy (FG4)
There you go, I know y'all done heard eugenics you know what I'm saying, it brings that to mind, you know like they trying to make the perfect person (FG4)

FGD participants also offered possible ways to counter conspiracy theories. Strategies proposed included providing more information and education about C&GT research to PLWH. Although they had no strong preferences about how to learn about such research, they highlighted in-person meetings, written material, including pamphlets, and engaging in social media as effective strategies to share information.

I want more information about what I'm getting into (…) before I jump into the fire (FG3)
You could do it just like you're having a meeting here (…) you know like a group meeting (…) they can have some people come down every so often and then have a group meeting (…) like we doing now. That would be good (FG3)

FGD participants wanted to talk to individuals who had undergone C&GT and hear about their experiences directly. This was perceived as an effective strategy because participants could relate to the messenger.

I said it would've been better if you came in here like you're introducing all of this to us but had somebody else that went through this (FG2)
Let me hear it from that person… that person know best what they going through and how they feeling (…) (FG2)

Across all FGs, the support and approval of participants' primary HIV care doctors would be paramount in making decisions about clinical research participation. The trust conferred to primary HIV care doctors was in sharp contrast to the distrust in medical research.

I don't think my doctor would advise that (FG1)
I'm going to ask my doctor about it (FG2)
I trust my doctor and everything but I just don't trust anybody now (FG4)

Some FG participants wanted to know why there was so much interest in cell and gene experimental research when HIV was already so easily treatable and managed. One FG participant thought medical advances were going too far.

Well… why they come out with that because you know they come out, they got some of that medication nowadays you know that like (…) the medication I'm taking now you know all my meds are combined in one tablet now I just take one tablet once a day (FG3)
I think it's at a great place from 30 years ago people living a long, people can live, people I mean people don't die from HIV no more. You know what I'm saying? People don't die from this no more, you know it's just like diabetes or whatever you know and why would they keep on tweaking it, tweaking it, tweaking it, tweaking 'till they can't tweak no more you know (…) medicine has just gone too far (…) you know what I'm saying medicine is just going too far (FG4)

Supplementary quotes are presented in Supplementary Data S2.

Discussion

To our knowledge, this is the first qualitative study to examine perceptions, beliefs, and acceptance of C&GT for curing HIV infection among PLWH. Our findings provide unique insights into the perspectives, preferences, and concerns of PLWH who have often been underrepresented in medical research, and yielded rich narratives anchored in the participants' experiences and knowledge. Our FG study extends the literature on HIV cure research by exploring perceptions of a specific HIV cure research modality, rather than investigating the acceptability of HIV cure research in general.[17,18,23] Data build on previous empirical research regarding acceptability of C&GT in non-HIV disease areas[24–28] and on recent U.S. surveys of public attitudes around gene therapy.[34,35]

Noteworthy findings include limited knowledge about this type of treatment (not a single participant had ever heard of C&GT), negative initial reactions to C&GT for curing HIV

infection, trust in primary HIV care doctors, and reluctance to do anything that would cause deterioration in their health status. Important concerns about possible risks of C&GT and analytical treatment interruptions were voiced. Participants' beliefs were influenced by conspiracy theories about biomedical research aimed at manipulating genes; yet they also offered constructive suggestions to increase community and end-user knowledge. Empirical data will guide future community engagement and sociobehavioral sciences in C&GT research and may have broader applicability to the field of HIV cure-related research (Table 2).

An important finding was that FGs participants reported limited knowledge and great hesitancy about C&GT. They held misperceptions that resulted in significant fears and concerns. This initial aversion mirrors fears about genetic technologies reported in other fields, notably for the treatment of sickle cell disease and Duchenne muscular dystrophy.[24,26] Initial reactions also parallel the low enthusiasm the American public exhibits about issues related to genes and genetics.[34,35] Our findings are generally consistent with previous social science research on HIV cure.[18] Skepticism regarding cure feasibility has been previously reported in a qualitative study in China.[36] Unwillingness to serve as a guinea pig has also been described in acceptability research in the HIV prevention field.[37] Findings are also consistent with gene therapy acceptability research in the oncology field, where participants had limited understanding and unrealistic expectations of therapeutic benefits of early phase trials.[38,39] Participants in our study reported willingness to try C&GT if it had already proven effective at curing HIV infection or it had been endorsed by trusted sources, such as HIV care providers or celebrities. The importance of long-term relationships built on trust with HIV physicians for HIV cure research in general and cancer research has been reported previously.[40,41]

Only a minority of individuals in our study reported readiness to undergo C&GT. Previous research showed variable opinions among PLWH in willingness participate in various types of HIV cure trials.[17] The majority of our participants were satisfied with their current antiretroviral treatment. The availability of well-tolerated, potent, and safe HIV medications tempered desires for curative interventions and lowered levels of clinical risk participants would be willing to take.[42] Decisions to test experimental HIV cure interventions are not divorced from the impact of HIV on daily life and participant's individual risk–benefit calculations.[43,44] Similar narratives were described in China and South Africa[36,45] End-user attitudes about gene therapy were consistent with those seen in other fields, such as Duchenne muscular dystrophy, where improving quality of life was seen as more desirable than finding a cure.[24]

Much of the hesitation about C&GT stemmed from its perceived irreversibility. A few participants felt some clinical risks were simply not worth taking. Results align with our previous social sciences findings, where significant clinical risks of HIV cure-related studies acted as deterrents to research participation.[17,18] Findings also confirm data seen in the non-HIV fields where patients favored the *status quo* over the risk of severe side effects.[24,26,28,34] Participants' questions about C&GT reflected limited understanding and scientific literacy about HIV cure research, consistent with previous sociobehavioral research[23] and U.S. public attitude surveys about genetic technologies.[34,35] Mistrust for clinical research emerged as a salient theme, based, in part, on the legacy of the Tuskegee syphilis study[15] and conspiracy theories.[16,46] Narratives were generally consistent with those seen in similar acceptability research on HIV vaccines[37,47–49] and gene therapy among Black/African American populations in the United States.[27,47]

Despite the best intentions of biomedical HIV cure scientists and safeguards to ensure C&GT research remains ethical, HIV cure-related research represent a relatively novel social phenomenon for many PLWH. End users ascribe meanings to clinical trial processes and outcomes based on historical events and current social experiences.[49] Disconnects between perception and reality often arise because of the sophistication of modern science and the rapid pace of novel scientific developments compared with the lack of scientific literacy.[50]

We must acknowledge several limitations in our study. First, FGs were conducted in a small sample of PLWH at a single HIV treatment center in the northwestern United States due to budgetary constraints, limiting generalizability. We would need a larger sample to confidently describe differences between subgroups. Our primary purpose was to explore meanings ascribed to C&GT as an HIV cure research modality and generalizability is not an inherent hallmark of qualitative research.[30] Second, sampling bias occurred as FGs were of variable sizes and participants were predominantly older unemployed Black/African Americans of low socioeconomic status who had lived with HIV for a long time. Our participants, however, represented individuals traditionally underrepresented in research and were mixed with respect to sex/gender. Future sociobehavioral research about C&GT should recruit younger, newly diagnosed PLWH, as well as sicker PLWH, including virologic nonresponders or those with concomitant severe medical conditions.[51] Third, group thinking, or agreeing with what participants previously said, most likely occurred, despite the facilitator's attempts to solicit input from all group members. Fourth, findings relied on self-reported hypothetical preferences. Future sociobehavioral research should attempt to understand longitudinal, lived experiences of actual C&GT participants. Fifth, we did not ascribe quotes to individual participants, compare data between FGs, conduct member checking posttranscription, nor monitor for data saturation, although we noticed overlap in core themes between FGs. While we asked about religious concerns about C&GT, data were too sparse to provide meaningful associations. We did not specifically delve into perceptions of somatic versus germ line gene editing technologies,[35] but realized in retrospect that this would have been a valuable contribution to the field given recent public outcries when CRISPR-Cas9 technology was reported to be used to gene edit human embryos.[12,13] Despite the above shortcomings, we believe our findings have internal validity with respect to the PLWH who participated in our FGs. Assessing public perceptions of ethical aspects of C&GT[3,4,52] in the context of HIV cure-related research was beyond the scope of our study.

Our findings have important implications for community engagement and education efforts regarding C&GT in HIV cure research (Table 2). Despite an active local community engagement program, no individuals had heard about C&GT approaches to HIV cure. This finding underscores that HIV

Table 2. Considerations for Community Engagement and Education and Sociobehavioral Sciences

Considerations for community engagement and education
HIV clinical research in general
Community engagement and education should not be an afterthought or seen as one-time events, but should be adequately funded to be sustainable and aimed at reaching groups traditionally underrepresented in research.
We need to build trust in clinical research in general, particularly in subgroups that may hold conspiracy theories. Emphasis should be placed on building trust between scientists and communities by encouraging the collaboration and participation of community representatives in the research process, including community engagement and planning. Biomedical researchers should be receptive and responsive to end-user concerns.[52] Whenever possible, clinical staff and outreach teams should reflect the racial and ethnic diversity of the populations researchers seek to engage and enroll.
Effective community engagement and education require adequate efforts, thoughtfulness, resources, and careful planning,[3] and must consult and involve local individuals who can speak to the needs and concerns of the diverse communities affected by HIV that can affect the conduct and successful implementation of any clinical research. This type of engagement helps promote transparency and confers legitimacy to the research endeavor.[4,35]
HIV cure-related research
There is a need to manage expectations around when a cure for HIV may materialize, and stress that early phase clinical research has limited personal clinical benefits to individual patients/participants and initial efforts rely primarily on altruism of study participants.[53]
Biomedical HIV cure researchers should provide a clear rationale to the public about moving experimental interventions forward into human testing.
The HIV cure research field will need to address community concerns around analytical treatment interruptions.
Given trust in HIV care providers, biomedical HIV cure research teams should consider engaging HIV care providers who will need to refer PLWH to participate in research.
C&GT HIV cure research
Given the complexity of C&GT research, we need to develop simple communication and educational materials that dispel misconceptions and explain how experimental interventions may work, including methods of administration, as well as their possible risks (i.e., futility, irreversibility, off-target effects, etc.) and benefits.
Testimonials from previous participants in C&GT research may also be an effective way to share information. They offer an additional pathway to build trust and overcome skepticism.
Other ways to aid understanding and demystify C&GT research beyond educational materials are to organize for stakeholders a tour or an open house of the clinic and laboratory where the research will be conducted; and to develop service learning projects for local students that are designed by both staff and community partners. These methods may give clinical staff the opportunity to get to know a community in greater depth while helping a community address its needs.
Videos can be an effective tool for education and outreach, provided they are kept brief and remain targeted to specific topics. Videos should employ a conversational, enthusiastic style to communicate effectively and enhance engagement. Creating guiding questions and other interactive elements to accompany videos may make watching them less of a passive experience.
Creating webpages with information about C&GT research with links to other resources may also prove an effective means to educate and engage people in the complex science. On such webpages, community members could post questions or comments and suggestions about the content, and clinical staff could offer ''electronic office hours'' so that community members can ask a question or receive an answer almost immediately. Informed consent forms and other supplemental information could be shared electronically.
More research is needed to understand end-user preferences for educational materials for C&GT, including how they should be tailored to specific subgroups, as well as contents and visuals.[26] To be effective, materials will need to incorporate the histories, texts, values, beliefs, and perspectives of people from different cultural backgrounds.
C&GT researchers working on HIV cure should partner with C&GT researchers working in other disease areas. An interdisciplinary approach to C&GT uses may help overcome specific HIV-related conspiracies that may surface.
Considerations for sociobehavioral sciences
More formative research is needed to understand evolving public perceptions on C&GT for curing HIV infection among diverse groups of stakeholders. Further qualitative work may delve deeper into acceptability of specific C&GT strategies and/or incorporate innovative methodologies (e.g., conjoint analyses).
Hypothetical acceptability research, as well as sociobehavioral research embedded within actual C&GT studies, should be considered important adjunct to ongoing biomedical research efforts alongside community engagement efforts. Sociobehavioral research should pay attention to the psychological and practical needs of PLWH. More research is needed on how to best support patients/participants in making decisions about participation[25] and to facilitate recruitment and retention efforts in trials.[26]
More attention should be paid to understanding how values, social representations, mental models, heuristic frames, and the public understanding of science[49,55,58] affect stakeholder perceptions and decision making.
More empirical research is needed on the ethical aspects of C&GT for curing HIV infection.[52]
Empirical research around perceptions, attitudes, and beliefs should involve the close collaboration of biomedical researchers, PLWH and community representatives, bioethicists, and sociobehavioral scientists. This type of multidisciplinary collaboration should celebrate and optimize the interdependency of stakeholders and will be critical in designing patient/participant-centered HIV cure-related interventions moving forward.[18,55]

C&GT, cell and gene therapy; PLWH, people living with HIV.

cure research education initiatives may not be reaching specific segments of the population. Additional efforts to reach underserved populations are needed. C&GT investigational approaches are highly complex, and clear lay-level communication materials must be developed. Biomedical researchers have much to learn from attempting to understand end-user perceptions and attitudes. Two-way dialog is needed to encourage mutual understanding and effective communication. We must continue to provide accurate, accessible information about HIV cure-related strategies so that community members can make informed choices and have realistic expectations around HIV cure research.[53] Effective community engagement and education also necessitates adequate support, attention, resources, and careful planning from a multitude of stakeholders.[3,54]

Results also underscore the need for a robust and multidisciplinary sociobehavioral sciences research agenda related to HIV cure (Table 2).[55] Additional qualitative and quantitative work should investigate acceptability, patient/participant values,[56] and lived experiences around specific types of C&GT approaches.[57] Innovative methods, such as conjoint analyses, should also be employed to assess the acceptability of specific attribute profiles of C&GT approaches as they move forward in preclinical and clinical development. As many PLWH may prefer complete elimination of HIV inside their body,[23] it will be important to reconcile what is biomedically feasible with what PLWH would find most valuable in terms of cure.

Conclusion

In sum, our study provides insights into perceptions and views about C&GT for curing HIV infection among men and women living with HIV in the northwestern United States. Perceptions were deeply embedded in lived experiences of PLWH and sociocultural meanings of disease and research. C&GT is a rapidly evolving field offering the potential for therapeutic and curative strategies aimed at managing persistent HIV. New technologies represent novel and sometimes contested social phenomena for end users and the general public.[3,49] Our findings underscore the importance of integrating sociobehavioral sciences during the development of strategies to cure HIV. Acceptability research will be necessary to guide community engagement efforts, support identification of potential study participants, and facilitate the design of effective and feasible research studies. Most importantly, understanding end-user perspectives is critical in designing interventions that are acceptable and attractive to populations of interest for HIV cure research.

Acknowledgments

The authors would like to thank all the FGs participants for their time, genuineness, and contributions. They are also grateful to Lindsay M. Legg, LPN, for her assistance recruiting FG participants. They wish to thank the defeatHIV Community Advisory Board and its coordinator, Michael Louella, for the role in their investigation. The impetus for this qualitative research is the direct result of their engaging communities affected by HIV in the cure-related research enterprise. It is solely due to their steadfast advocacy for more focus on people's perceptions of cell and gene therapy as a potential HIV cure strategy that this research was conducted; and for their efforts and their willingness to work as equal partners with our research staff, they are to be commended. This project was supported by the defeatHIV Collaboratory (AI126623) and the University of Washington/Fred Hutch Center for AIDS Research (AI27757), and was conducted in close collaboration with the defeatHIV Community Advisory Board.

Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Data S1
Supplementary Data S2

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