If We Build It, Will They Come? Perceptions of HIV Cure-Related Research by People Living with HIV in Four U.S. Cities: A Qualitative Focus Group Study

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Abstract

Global interest and investment in the search for an HIV cure has increased. Research has focused on what experts refer to as a sterilizing or eradicating cure, where HIV is eliminated from the body, and on what is often called a functional cure, where HIV remains, kept durably suppressed in the absence of antiretroviral treatment and therapy (ART). Many believe that a functional cure is likely to be found first.

HIV cure studies will require active participation by people living with HIV (PLWHIV). Their desires and perceptions will be important to effectively recruit study participants and for the uptake of any future strategy that demonstrates safety and efficacy. The perspectives of PLWHIV are essential to advancing HIV cure research, and they should be taken into consideration as biomedical research advances. We conducted 10 focus groups in four U.S. cities, eliciting perspectives of PLWHIV on HIV cure and cure research. Most participants conceived of a cure as eradicating, and felt favorably toward it. In addition to the physical benefits of a potential cure, participants valued the possible de-stigmatization related to no longer living with HIV, liberation from concerns about transmitting HIV, and freedom from the burden of daily medication. Many participants did not regard a functional cure as an improvement over controlling HIV through ART, were distrustful about viral rebound potential, and noted concerns about medical complications and accompanying psychological distress. Some felt that the risks of HIV cure research were not worth taking. Many were skeptical about science's ability to eliminate HIV from the body.

Keywords: community perceptions, HIV cure research, cure, HIV cure, people living with HIV, PLWHIV, focus groups

Introduction

THE HIV/AIDS EPIDEMIC CONTINUES to affect millions of people worldwide despite the scaleup of antiretroviral treatment and therapy (ART) and the advent of new biomedical prevention methods.¹ Treatment access has increased dramatically, more than doubling since 2010 with 17 million people

accessing treatment in 2015¹; however, roughly half of those living with HIV globally remain without treatment,¹ and those who are on treatment must maintain a lifetime of daily adherence to medication.² HIV/AIDS-related deaths decreased by 43% since global treatment targets were set in 2003, yet there were roughly an additional 2 million new HIV infections in 2015, leaving about 37 million people living with HIV (PLWHIV)

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worldwide.¹ In the United States, the Centers for Disease Control and Prevention estimates that only 39% of individuals aware of their HIV infection are receiving care, and only 30% are virally suppressed.³ Despite the need for ever-improved HIV treatment, most Americans have access to the current, highly effective medications through either private insurance or publicly funded programs, such as the AIDS Drug Assistance Program, Medicaid, and Medicare.

Despite recent and ongoing scientific advances to find a cure for HIV infection, to date, only one person, Timothy Ray Brown, has been cured as a result of a bone marrow transplant 10 years ago from a donor homozygous for the delta32 CCR5 mutation—a rare but naturally occurring trait that prevents HIV from infecting a patient's immune cells.^{4,5} Although researchers have not been able to replicate this outcome in other individuals, Mr. Brown's case has been inspirational, spurring investment in the search for a cure.

Biomedical HIV cure researchers often speak of two types of cure: a “sterilizing” cure, where HIV is completely eradicated from the body, and a “functional” cure, where, in the absence of medication, viral replication remains durably suppressed, transmission does not occur, and harm is not done to the body by the virus.⁶ Although HIV cure research currently encompasses several strategies, such as gene modification to make the body resistant to HIV or to enhance the immune system's ability to clear or control HIV through engineered stem cells, T cells and antibodies,⁷ HIV latency reversal, a variety of immune-based therapies, and early treatment, the notions of “sterilizing” or “eradicating” versus “functional” cures have been used for both scientific discussion and community engagement efforts around HIV cure research. For the most part, scientists and community stakeholders are skeptical of the ability to achieve a sterilizing or eradicating cure any time in the near future, and most believe that a functional cure will be easier to achieve.⁸ Reflecting this general direction, current research priorities of the International AIDS Society Toward a Cure initiative include understanding the molecular biology of HIV latency, immunology of HIV persistence, models for HIV cure or sustainable remission, remission in the pediatric population, cell and gene therapy, novel markers to quantify HIV persistence, social science research to better understand patient perspectives and potential engagement, and health systems research.⁷

Since HIV cure science is still very much an emerging field of research, it makes sense to consider what HIV cure efforts mean to PLWHIV and how they feel about them. The perspectives of PLWHIV, beginning with those related to language and nomenclature of HIV cure,^{9,10} are essential to advancing HIV cure research for at least three reasons. First, PLWHIV perspectives can help guide researchers in their pursuits of interventions that would be most acceptable to PLWHIV—an issue at the heart of all efforts to ensure the effectiveness of efficacious interventions.¹¹ Second, HIV cure perspectives among those who would be offered a potential cure can help ensure that research is conducted ethically, with proper participant understanding and expectations.^{12,13} Third, understanding factors that contribute to or detract from the interest and willingness of PLWHIV to participate in HIV cure studies is likely to have a positive impact on recruitment and retention in clinical trials.^{14,15} However, there is a dearth of published research on the knowledge, attitudes, and perceptions of PLWHIV regarding HIV cure research in the United

States, despite more than 125 clinical studies having been implemented to date.¹⁶ The HIV cure field can learn from the experiences of vaccine research, microbicide research, and treatment as prevention research about the importance of conducting acceptability and other social science research concurrently with biomedical exploration and embedding social science research within clinical trials.^{17,18}

To explore perceptions related to HIV cure research, we conducted 10 focus group discussions (FGDs) with PLWHIV in four U.S. cities. The goal of this research was to gain a better understanding of how PLWHIV think and feel about the prospects of a cure to inform current and future scientific efforts toward a cure. Our research team included members from the three initial Martin Delaney Collaboratories Toward an HIV Cure Community Advisory Boards: Delaney AIDS Research Enterprise (DARE), Collaboratory of AIDS Researchers for Eradication (CARE), and defeatHIV.

Materials and Methods

FGDs are a useful formative research method for gathering information on attitudes, perceptions, and feelings from designated stakeholder populations. They are effective at assessing community-level understanding, including how people ascribe meaning to various concepts. They also provide a means of collecting a large body of data within a short period.¹⁹ We conducted a total of 10 FGDs to ask PLWHIV questions about their definitions of cure, their attitudes toward eradicating and functional cures, expectations of biomedical HIV cure researchers, and factors that would affect their willingness to participate in HIV cure-related studies.

Using a semi-structured protocol (Table 1), we conducted four FGDs in Seattle WA, two in Los Angeles CA, one in San Diego CA, and three in Durham NC, between January and June 2016. We selected these cities because each represented clinical research sites for the Martin Delaney Collaboratories Toward an HIV Cure, an initiative sponsored by the United States National Institutes of Health, to advance the science on HIV cure research. In total, we recruited 76 participants self-reported to be living with HIV, between the ages of 18 and 79 years. They were 60.5% male, 35.5% female, and 3.9% transgender. Respondents were ethnically diverse: Of the 75 people who provided information, 40.8% were Caucasian/White, 39.5% African American/Black, 9.2% Hispanic/Hispanic Descent, 5.3% Mixed, and 3.9% American Indian or Alaskan Native.

Individuals considered eligible for participation were at least 18 years of age, living with HIV, living in the selected metropolitan areas, willing to provide consent and give their opinions about HIV cure research, comfortable discussing HIV cure research with other PLWHIV, and willing to keep information shared in the focus groups confidential. We intentionally recruited groups previously under-represented in HIV cure research, including women, gay men of color, young adults, long-term survivors, and African Americans/Blacks. We tried to recruit a group limited to transgender women living with HIV at the Seattle research site; however, logistical constraints and stigma made this unfeasible. Trans-women with HIV did not want to identify themselves as HIV-positive in front of others. The four Seattle, WA, focus groups were diverse with respect to age and gender, with representation weighted toward older (50+ years) and younger (<30) individuals as a result of

TABLE 1. FOCUS GROUP TOPIC GUIDE

Interest in finding a cure for HIV has been growing. Recently, there has been funding and scientific progress toward finding a cure for HIV one day. We would like to find out how people living with HIV view the possibility of an HIV cure, HIV cure research in general, and interest and willingness to participate in HIV cure studies.

Particularly, we are interested in finding out more about:

- Your thoughts and feelings about a possible HIV cure
- Your thoughts on possible risks and benefits of HIV cure research

All questions listed next will be asked. Prompts are optional and will only be used if necessary to draw out additional discussion.

1. What do you think of when you hear the words “HIV cure?”
 - a. Additional prompts: (What does HIV cure mean to you? How does the idea of an HIV cure make you feel?)
2. When researchers talk about HIV cure, they sometimes use the words “Sterilizing Cure,” meaning HIV would be completely gone from your body. Sometimes, they use the words, “Functional Cure,” meaning that HIV is still in your body, but it is not doing any damage to your body, your immune system is working to keep you healthy, and you cannot transmit the virus to anyone else. How does each of these cure ideas make you feel?
 - a. Additional prompts: (What words would you use to describe each of these?)

Thank you for taking the time to answer these questions. Your participation in this focus group greatly contributes to the research project and to increasing our understanding around the issues affecting participation in HIV cure studies. Your answers will be compiled with the answers of all other focus group participants. Please feel free to contact us at anytime if you have any questions about this focus group or the research project.

Please remember you have agreed not to share information with anyone about anybody who was here or anything that was said today. Thank you again for coming today and sharing your thoughts with us.

the demographics included: One group was limited to individuals living with HIV for 20 or more years; one was limited to women; one included gay men of color (all Hispanic due to location); and one was limited to people between the ages of 18 and 29. In Los Angeles, CA, two focus groups were conducted, one with women exclusively, and the other mixed with respect to gender; both were ethnically diverse. We conducted one focus group in San Diego, CA, that was predominantly with older gay and bisexual men; all participants were Caucasian/White. We conducted three focus groups in Durham, NC, that were diverse with respect to gender, and composed mostly of African American/Black participants. All sites carried out recruitment by using Institutional Review Board (IRB)-approved fliers, emails, phone scripts, and through word of mouth. The focus groups were conducted in private meeting rooms in HIV clinics, community-based organizations, and home settings.

Table 2 provides a summary of the demographic focus of each group, and Table 3 details the demographic variables of all focus group participants.

Trained community co-investigators led each of the focus groups. Focus group sessions took ~90 min each. Investigators introduced themselves as members of their respective Community Advisory Boards, and, in some instances, provided additional affiliations. All co-investigators perceive themselves to be community advocates and include a mix of people living with and without HIV. Two focus group facilitators were male, two were female, and all were white. Focus group assistants were White, Black, American Indian, and Hispanic. With a few exceptions, the majority of participants and investigators were unknown to each other. All focus group leaders followed the same topic guide (See Table 1 for the topic guide). Broad topic themes were framed by the questions in the topic guide, that is, feelings about an HIV cure, expectations of researchers, facilitators and barriers to research participation, and issues related to mental health and study participation. Themes that emerged within these areas of inquiry were derived from the data. Participants received \$15 compensation for their participation in the form of a gift card. We provided food at all focus group meetings. All study participants signed an informed

consent form, completed a demographic information sheet, and received a project fact sheet before the session began. Because HIV cure research is a relatively new and complex concept, we chose to focus on broad organizing topics, such as “sterilizing” versus “functional” cure for the discussion, rather than delving into specific HIV cure research strategies.

A research team member took detailed notes during all of the FGDs. Each discussion session was also audio recorded and later transcribed verbatim. Our analytic methods were informed by a combination of two common approaches in qualitative social science: grounded theory (to understand the realities anchored in the view of respondents) and phenomenology (to capture the essence of a phenomenon or the lived experiences of individuals).¹⁹ We employed applied thematic analysis²⁰ combining a priori and emergent codes to analyze the data. Two researchers collaborated on data coding. One researcher applied the thematic codes to the data, and a co-investigator subsequently examined all codes for all transcripts to determine agreement with them. Discrepancies were resolved via discussions and consensus between them to reach consistency in interpretation of the data. We used MAXQDA

TABLE 2. FOCUS GROUP COMPOSITION

Seattle, group 1	Women, mixed race
Seattle, group 2	Mixed gender, long-term survivors (20+ years living with HIV), mixed race
Seattle, group 3	Gay men/non-binary, Latinx
Seattle, group 4	Young gay men (under 30), mixed race
Los Angeles, group 1	Women, mostly black, one white
Los Angeles, group 2	Gay men/one woman, mixed race
San Diego	Gay men/one woman, white
Durham, group 1	Mixed gender, mixed race
Durham, group 2	Mixed gender, African American
Durham, group 3	Mixed gender, African American

TABLE 3. DEMOGRAPHIC CHARACTERISTICS OF FOCUS GROUP PARTICIPANTS, UNITED STATES, 2016

	<i>Sites</i>				<i>Total</i>	<i>Percent (total)</i>
	<i>Seattle, WA</i>	<i>Los Angeles, CA</i>	<i>San Diego, CA</i>	<i>Durham, NC</i>		
<i>n</i>	32	10	9	25	76	
Gender						
Male	21	4	8	13	46	60.5
Female	9	5	1	12	27	35.5
Transgender (male to female)	0	1	0	0	1	1.3
Transgender (female to male)	1	0	0	0	1	1.3
Gender queer/non-binary	1	0	0	0	1	1.3
Did not specify	0	0	0	0	0	0.0
Age						
18–29	7	0	0	1	8	10.5
30–39	1	1	0	2	4	5.3
40–49	3	2	0	6	11	14.5
50–59	8	4	3	9	24	31.6
60–69	5	2	4	2	13	17.1
70–79	3	0	1	0	4	5.3
Did not specify	5	1	1	5	12	15.8
Ethnicity						
Caucasian/White	17	3	9	2	31	40.8
African American/Black	5	4	0	21	30	39.5
Hispanic/Hispanic Descent	6	1	0	0	7	9.2
American Indian or Alaska Native	2	1	0	0	3	3.9
Native Hawaiian or Other Pacific Islander	0	0	0	0	0	0.0
Asian or Asian Descent	0	0	0	0	0	0.0
Mixed	2	1	0	1	4	5.3
Other	0	0	0	0	0	0.0
Did not specify	0	0	0	1	1	1.3
Year diagnosed with HIV						
1981–1989	11	2	5	3	21	27.6
1990–1999	11	4	3	5	23	30.3
2000–2009	4	0	0	5	9	11.8
2010–2016	5	3	1	4	13	17.1
Did not specify	1	1	0	8	10	13.2

(version 12.1.3; Berlin, Germany) for data analysis of the transcripts.

The study received ethical approval from the Non-Biomedical IRB of the University of North Carolina at Chapel Hill (study #14-2672).

Results

Participants had generally not been exposed to much information about the specific methodologies being explored for either an eradicating or a functional cure. They had vague ideas about “being cut open,” cell manipulation, medication, or a “heavy duty” intervention of some type being part of HIV cure research. Some had difficulty grasping what a functional cure would actually be like, whereas others saw it as similar to being suppressed on antiretroviral therapy. The term “functional cure” itself was meaningless to many in our sample.

Although we did not compare results from each group, a few high-level themes emerged across all groups. Most FGD participants indicated a desire for a cure for HIV infection. Their concept of cure was consistent with an eradicating cure, with HIV eliminated from their bodies. Many were skeptical about the durability of a functional cure, and had significant fears related to potential viral re-emergence. A number be-

lieved that a cure would be liberating in multiple ways, especially from stigma. A few indicated that they were unlikely to give up their antiretroviral medications in favor of any methodology that had not had its durability tested for a number of years. This was especially true for those who had experienced challenges achieving stable health.

Some differences in emphasis were observed across FGDs. For example, in Seattle, Hispanic gay male participants appeared to care more about the reputation and qualifications of the researchers and their affiliated research institutions than the other groups, whereas women raised concerns about the potential impact of cure strategies on reproductive health. Given the small number and diversity of group membership, we did not conduct a comparative analysis of results across groups. Rather, we were interested in a qualitative understanding of overall emerging community perceptions related to HIV cure research, and our data are presented accordingly. Supplemental quotes by theme can be found in Table 4.

Definitions and preferences for an HIV cure

When asked, “What do you think of when you hear the words HIV cure?” most participants responded with statements

that were consistent with what is typically referred to as a sterilizing or eradicating cure. A few described features of a functional cure, in which residual virus remains in the body. Substantial preference for a cure that completely eliminates HIV from the body from our sample of focus group participants was also expressed.

“A cure, for me, it means complete eradication—that I can then never have to discuss it again.” (Seattle, group 1)

“Cure means to me to eliminate or not have this disease.” (Los Angeles, group 1)

“And as far as the two different kinds of cures, I’m definitely more interested in the sterilizing cure that would eradicate and makes it so that it’s no longer in your system ... and that you are not able to give it to anyone else again, as opposed to something else that’s functional and then, you are waiting for it to be out of remission on a shoe drop, so...” (Seattle, group 1)

Setting aside the issue of viral elimination versus durable viral suppression, a handful of participants put forward key desired features of a cure. These included putting a stop to the damage HIV does in the body, no longer needing to take HIV medication, becoming immune from future HIV infection, and permanently eliminating the risk of transmission to others. For instance, participants said:

“I really feel like I know that the cure could go two different ways, you know. It could either stop HIV in its tracks in our body, even though we’d still have it; we wouldn’t be able to infect anybody else, or, there’s the other arm of it, where, you know, it would just be completely gone, and wouldn’t that be wonderful.” (Durham, group 3)

“I would truly love to be off the medications I’m sick of them, I am so sick of them I look at them and I’m like do I really want to take those today? And then I’m like I’ll take them and then I go ahead and take them I can’t say what it would be not to take medications, I know one thing I wouldn’t have to worry about did I take my meds today or trying to remember did I take my meds or to know that it’s completely out of my body and I don’t have to worry about taking meds....” (Durham, group 2)

Many expressed apprehension about a functional cure, raising concerns about the anxiety of waiting for the virus to reactivate, or fear of the virus returning with a vengeance, possibly resistant to treatment. Some preferred the control they could maintain by taking their medications over a functional cure of uncertain duration. A few welcomed the idea of relief from their daily medications, and would embrace it as an improvement. For some, a functional cure seemed like a long-acting HIV treatment option, and not a cure *per se*. The fear of becoming unknowingly infectious again through resurgent virus was one of the key reasons that individuals were distrustful of a functional cure. For this reason, along with health-related fears, there was strong preference for HIV to be completely gone from their bodies, with varying levels of doubt about the feasibility of eliminating every last viral particle, or knowing with certainty whether or not complete eradication had occurred. For instance, focus group participants mentioned:

“So, okay, if I go through this process and everybody knows we have latent virus in our body, then if I stop taking my medication and I go into “remission” for a while, then how is the virus gonna come back? And how sick will I be? And is there going to be medication for me? I mean that’s a big

risk. You know, I’m already resistant to a lot of medications now.” (Los Angeles, group 1)

Even those who expressed a preference for a cure that eliminated HIV from their bodies expressed some trepidation about being able to have confidence that every last trace of HIV was truly gone and would not re-emerge someday.

“I think either of them are both still kind of nerve wracking because if HIV is in every cell of our body, how do they seriously know that there’s not one little dude in there, somewhere, you know, under your fingernail or like somewhere that might come back out, so I think after like 20 years of a cure being out there, I might have like full confidence that it might not relapse...” (Seattle, group 1)

“Because sterilizing cure would eliminate the possibility of that person to pass it on, that’s the importance.” (Seattle, group 1)

In sum, definitions of and preferences for an HIV cure among FGD participants were chiefly the same. Much of HIV cure research is currently focused on methodologies that are more likely to achieve a functional cure than an eradicating cure. However, many PLWHIV did not endorse the concept of a functional cure as superior to ART, finding the anxiety of an unpredictable possibility of undetected viral reactivation less preferable to the viral suppression they believed they could maintain via medication adherence that was in their control.

Linguistic connotations and preferences

Several people spoke about not liking the term “sterilizing,” as sterilizing had negative connotations for them.

“I’ll just add that we need a better word for sterilizing cure, just makes certain parts of my body” (Durham, group 2)

“For me, sterilization is a scary word for me. I don’t like the word sterilization.” (Seattle, group 3)

Some equated a functional cure with cancer remission, and the concern that it could re-occur at any time. Although the term “remission” is useful because of its familiarity (e.g., in the field of oncology), several participants spoke about that word being “scary.” The concept of remission includes the possibility of recurrence, and it was inconsistent with how people think about a “real” cure. Focus group respondents also associated the term with people they knew who had had cancer that went into remission; in some instances, in their experience, the cancer returned, and was fatal. The following statements illustrate this point:

“...I don’t think I want mine to be in remission because it would be always in the back of my mind it’s gonna come back.” (Seattle, group 4)

“... My mom had the breast cancer and it went from her breast to her liver to her brain you know and it went into remission there for a while and then when it came back it just came as a vengeance and..... but again, it’s in the back of your mind, is it gonna come back? I have to really know a lot about this in order to make a proper decision, because I don’t want to go off of it [ART] and then have it come back even worse, you know.” (Seattle, group 3)

The negative associations that individuals have with remission being followed by recurrence and death may outweigh the value of the word’s familiarity when communicating about the residual quiescent virus.

TABLE 4. SUPPLEMENTAL QUOTES, PERCEPTIONS OF HIV CURE RESEARCH FOCUS GROUP, UNITED STATES, 2016

HIV cure definitions	<p>“It means that procedures have been developed that would eradicate or eliminate HIV.”</p> <p>“Hmmm..... To be able to give you maybe a pill or something for it to clear it up and make it disappear and no longer exist. A cure for me is also not to be able to happen ever again, if that’s possible.”</p>	<p>Seattle, group 2</p> <p>Seattle, group 1</p>
Preference for eradicating/ fears of functional cure	<p>“I don’t want no one to come to tell me, “Oh, it’s gone,” and next month, or a year or so, it’s back twice as bad. I don’t want that. Let me deal with it like I did right now, and I’m doing good; I’m 68 years old and I’m doing good.”</p> <p>“I don’t know about functional. I mean, it’s just, you know, if there’s still a virus in there and it does decide to just by chance come back and release itself and come back unexpectedly, then what? You know you go back on meds and maybe the meds don’t work because you have the, uh, what’s the word, I can’t think of it, resistance of it.... The virus, the viruses can always evolve themselves into a super virus, yeah, but the eradication that would be the best, I think, definitely, you know.”</p> <p>“A functional cure won’t end stigma—you would still need to disclose.”</p> <p>“A functional cure freaks me out. How long will it last? What if it activates again and I didn’t know?”</p> <p>“Rather have the sterilization cure if it’s permanent and free from future infections.”</p> <p>“Functional feels like a time bomb.”</p> <p>“I prefer sterilizing. Makes me less depressed—feel more positive.”</p> <p>“A functional cure freaks me out. How long will it last? What if it activates again and I didn’t know?”</p> <p>“I would really like to see a functional cure; I think that will come first.”</p> <p>“I’m having a very hard time trying to visualize this functional.....As far as I’m concerned, I’m undetectable so I have a functional cure right now...”</p> <p>“Eradication is the best, that’s the best, it is because I don’t get the other, I really don’t.”</p> <p>“Maybe the scientists think we’re stupid, why are we even bothering with the functional thing, that’s what I want to know, it’s something ...”</p>	<p>Los Angeles, group 1</p> <p>Seattle, group 2</p> <p>Seattle, group 4</p> <p>Seattle, group 4</p> <p>Seattle, group 3</p> <p>Seattle, group 4</p> <p>Seattle, group 3</p> <p>Seattle, group 4</p> <p>Los Angeles, group 1</p> <p>Seattle, group 2</p> <p>Seattle, group 1</p> <p>Seattle, group 1</p>
Liberating aspects of an HIV cure	<p>“What I think about a cure, there is so much that, like, is folded into that what would life be like if we had a cure. I mean, even the relationship choices I’ve made since I became positive..... I may consider that I have more opportunities, you know. Um, I mean because a lot of us selectively date, you know, because we just don’t want to deal with somebody who doesn’t know or doesn’t understand.....”</p> <p>“What comes to mind where I hear cure is.....I guess getting rid of the stigma of living with it that you get from other people.”</p> <p>“And also cure means to me to get busy, because, you know, I’ve been living my life like, you know, I had limited time anyway, so I never really finished college and pursued the fact I’m gonna die anyways so I’ve heard, yeah, a cure means it’s time to get busy, catch up the lost time you know.”</p> <p>“I could just have that opportunity to just have a normal life again.”</p> <p>“What I think about being cured... is my God gave me another chance to right what I did wrong.”</p> <p>“...be able to travel the world, you know. I want to travel and do things and live places where there’s not medication.”</p> <p>“It’s hmmm, it’s like to me, if they find a cure, it’ll make the world a whole lot better and it would make the...it would make people feel better about themselves. It’s not just two separate classes. People with not HIV and people with HIV. You know, it’s just... it’ll make it all... it will just make us all one. You know. We won’t have two separate classes.”</p> <p>“Well I’m excited you know, I’m just excited that we’re even talking about this you know.”</p>	<p>San Diego</p> <p>Seattle, group 2</p> <p>Durham, group 1</p> <p>San Diego</p> <p>Los Angeles, group 1</p> <p>San Diego</p> <p>Durham, group 1</p> <p>Los Angeles, group 2</p>

(continued)

TABLE 4. (CONTINUED)

Feelings about an HIV cure	“It’s kind of bittersweet too. I don’t feel so secure in the idea of a cure, just because it is scary, it’s so unknown.”	Los Angeles, group 1
	“Um, uh, I personally, um, it doesn’t really matter if they find an HIV cure, but I’m glad they have a medication that will prolong our lives; I’m very satisfied with that.”	Durham, group 2
	“For me the sterilizing thing, and only because I sat in a talk and I’ve met Tim. It’s frightening as shit, because it’s a very rad. I mean stem cell transplant is a real radical thing that to cure your HIV you’re basically like going to the edge of death...”	Los Angeles, group 1
	“Well I’m going to hope for it because in the six years that I’ve been infected I’ve seen like massive amounts of breakthroughs already, so I think it will happen within my lifetime.”	Los Angeles, group 2
	“Maybe when I’m 90, for my grandkids. Probably not in my lifetime.”	Seattle, group 1
	“Not going to happen.”	Los Angeles, group 2
	“Well I’m excited you know, I’m just excited that we’re even talking about this you know.”	Los Angeles, group 2
	“When I hear the word HIV cure, thankful and grateful.”	Durham, group 1
	“I don’t like the word sterilizing.”	Durham, group 2
	“.... and then I started thinking about cancer and remission, you know, and then, cause my mom, she had cancer, and she had remission, and then it came back, and then she die, you know. So, you know, that’s in that state is saying that in remission it’s still there but it could also come back you know so I tell you know, like my friends with cancer, I have a lot of friends with cancer and they, um, they go into remission and then it comes back, Stage 4 cancer, and then they’re gone, you know. So that’s a good word, but it’s not a cure, you know, because I would want a cure for real, you know, ‘cause right now I am in remission and I’m doing fine. I’m, I really want a cure, so I’m having to think in the back of my brain, is this gonna come back? You know I want to be able to be free, I ain’t going to be out there trying to get it again, but I just want to I want to be free of it, 100 percent.”	Seattle, group 2
Language		

Liberating aspects of an HIV cure

Some respondents described how their lives would change with a cure. The most frequently mentioned benefits of a potential cure were no longer needing to take medication and not being able to transmit the virus to anyone. Other perceived benefits cited by participants included sexual freedom and an end to stigma. These potentially liberating aspects of a cure for HIV are highlighted by the following participant statements:

“Not having to take medication every day and side effects and all of that, you know; yeah it would be a blessing for me.” (Durham, group 2)

“But just having the freedom to know, you know, I could have sex and not give someone HIV, it would just be a great burden off my shoulder.” (San Diego)

“I have thought about, you know, if I was cured what would I be doing right now? My whole life would change. My sexual life would change. I mean, oh my God, I’d get to have sex again. I mean, wow, you know.” (Los Angeles, group 2)

Others talked about a cure being an opportunity for a second chance, for transforming their lives, and for being freed from burdens such as disclosure of HIV infection to others.

“When I think about a cure, I can’t help but think about my daughter and about how me being positive affects her, and even though she’s not positive I know she’s still gonna possibly have

to deal with issues with probably her friends or their parents when she gets to be school age because I’m positive. But for that to not be an issue, to have to explain it to her and try to get her to understand, it would be wonderful.” (San Diego)

“It’s... the idea of a cure is like, oh wow, I could be normal again. So yeah, living without stigma of being positive, having to disclose, I mean, it’s amazing how many people are very accepting of, but still, it’s like they want to go on a date—oh and by the way, um...” (Durham, group 1)

These data illustrate the desire of PLWHIV to be free from HIV itself, as well as from its associated stigma (for themselves and others), imperative to disclose, burden of taking medication, and inhibition on sexuality.

Aspirations and fears about an HIV cure

Participants at all sites expressed a broad range of feelings related to an HIV cure, including gratitude, excitement, ambivalence, indifference, discomfort, and apprehension. Fears related to the kind of medical procedures of a cure might entail potential side effects, potential HIV recurrence of a more severe nature, loss of ART efficacy, fear of identity loss, and fear of the unknown. A few individuals who had lived with HIV for many years were hesitant about what it would mean for them to be someone who was not living with HIV, as this had become part of their identities. It was difficult for them to wrap their minds around what it would be like to be cured of HIV

infection. Some felt that antiviral medication was, in a way, a functional cure, as their viral load was currently undetectable and they believed that they, therefore, could not transmit the virus to others.

“Oh, lord, I think about what a blessing it would be.” (Los Angeles, group 2)

“I would love to be cured.” (Durham, group 1)

“I don’t feel so secure in it. As a long-term survivor, this is a new conversation for me. I wouldn’t have to struggle anymore. That struggle’s been my identity. It’s bizarre. I don’t know how it will be to not have HIV. I would need to go to therapy.” (Seattle, group 2)

“Because basically it’s something new and you never know you know if it works or if it’s going to take your life.” (Los Angeles, group 1)

“I think we already have one because all the pills that keep your viral load and you can live a normal lifespan.” (Seattle, group 2)

Some were optimistic about the likelihood of achieving a cure, others were pessimistic about seeing a cure in their lifetimes, and a few felt that more work toward a cure should have begun long ago.

“But yet, to me it’s very exciting, you know, like I said, after 32 years I’d like to be able to one day come back to my daughters and say I’m cured.” (San Diego)

“I have no belief that I will be cured before I die; that’s sad.” (Seattle, group 1)

“Um, wow. Part of me thinks well it’s about damn time that we’re seriously looking at this.” (Seattle, group 1)

Desire for the medical, social, and psychological benefits an HIV cure could potentially bring was clearly tempered by skepticism that a cure was achievable, and fears that someone could appear to be cured for a period, only to find out later that they were not. This appeared to be perceived as a worse outcome than the current status quo of being able to maintain viral suppression on antiretroviral therapy.

See Table 2 for additional emblematic quotes from this focus group study, by theme.

Discussion

This study adds to the literature on the social sciences of HIV cure-related research by empirically exploring perspectives of PLWHIV regarding desirability and implications of either an eradicating or functional HIV cure. Grossman *et al.* have pointed out the necessity of exploring these perspectives as the biomedical science progresses,²¹ whereas to date, few empirical assessments have been conducted. Perceptions of PLWHIV and acceptability of HIV cure interventions are sociologically important to understand in and of themselves, and also will affect participation in clinical research and uptake should a cure be discovered. As in the field of HIV vaccine research, formative research to access and understand evolving public discourse on HIV cure studies may provide an empirical foundation for knowledge translation and community engagement strategies to support the long-term process of HIV cure development.²²

Most focus group participants felt that the only meaningful cure for HIV would be one that eliminates all HIV from the body; virologic suppression of ART with residual virus that could return was seen as less ideal and less acceptable. Some respondents felt uncertain that they could trust that the virus

was truly and permanently eliminated, whereas the majority felt very favorable toward the concept of individual viral eradication. This is consistent with findings from China, the Netherlands, Australia, and the United Kingdom.^{23–27}

One important implication of this study is that HIV cure researchers, social science researchers, funders, policy makers, and review bodies should pay more attention to the level of ambivalence that there appears to be among PLWHIV regarding a functional cure, as well as to their concerns about durability and potential viral rebound. This strong and nearly universal dissatisfaction and distrust in the notion of a functional cure is significant, with a number of participants indicating a preference for remaining on ART over a functional cure. The social and psychological risks, along with the medical risks of viral rebound after a period of believing oneself to be cured, are substantial. In addition, the concerns related to potential viral rebound associated with a functional cure also have ethical implications for when and how to conduct analytic treatment interruptions in the course of HIV cure-related research.

Although distrust and fear among PLWHIV of a methodology that would durably suppress but not eliminate HIV is important to take into consideration and to tend to, it is certainly not the only consideration that should drive the HIV cure research agenda. Given the incremental nature of scientific discovery, many believe it likely that a functional cure will be found before an eradicating one.²⁸ More exploratory work on intervention acceptability and potential challenges to uptake of these interventions should be incorporated into clinical HIV cure studies. Although the numbers of PLWHIV who have expressed their opinions on this globally are relatively small, their sentiments have been largely consistent. The apparent mismatch between distrust among PLWHIV toward durable control as a cure strategy and investment and scientific interest in these strategies is worthy of additional exploration.

The sense of liberation that participants associated with an eradicating cure should also be noted. For many, a cure would not only end their physical suffering, and remove the burden of lifelong HIV medication, but also alleviate the psychological and emotional burdens they carry, including HIV-associated stigma. In addition, a cure would help address the constraints that participants felt in their current lives, such as relationship or residency choices (i.e., living proximate to treatment), especially if a cure rendered them antibody negative, non-infectious, and unable to be re-infected. This finding parallels that found in other explorations related to the meaning of cure among PLWHIV.^{13,23,24} For instance, Moodley *et al.* found that South African PLWHIV felt that living with the challenges and stigma of having HIV meant being “unable to live freely” and viewed cure as a “return to normality” with no need to take medication again.²⁹ These concepts were virtually identical to those expressed by a significant number of focus group members. Similarly, an informal interactive activity conducted in person by several Martin Delaney Collaboratory community advisors at the 2016 International AIDS Society conference in Durban, South Africa, found that, among 244 responses to the question, “What would an HIV cure mean to you?” 35 (14.3%) specifically mentioned freedom or liberation and 10 (4%) explicitly mentioned an end to discrimination and/or stigma.³⁰

Further, according to Tucker *et al.*, cure is often narrowly conceived in biomedical terms, in isolation from social and

psychological meanings of illness.⁹ The language we use to discuss cure is important, as words conjure different emotional responses and may even have ethical implications related to choices that people make. For instance, decisions regarding participation in HIV cure research may be influenced by “curative hope” or “curative misconception.”⁹ In our study, focus group participants expressed strong emotional reactions to terms used in HIV cure discourse. The objection by some PLWHIV to the term “sterilizing,” which is often used to discuss an eradicating cure, was reminiscent for them of sexual sterilization and had a negative connotation. The term “sterile” was also seen as cold or empty. As community advocates, we recommend against continued use of the word “sterilizing” in association with HIV cure-related research. Bearing in mind the historical policies of forced sterilization of poor women and women of color,^{31–34} as well as more recent attempts to forcibly sterilize women living with HIV,^{34–36} it seems important to be aware of all the meanings associated with this word—especially for individuals who may be potential study participants or eventual beneficiaries of a cure. In an effort to create a culturally relevant shorthand for what is meant by functional cure, many refer to it as analogous to remission, a concept familiar to most from the cancer field⁹ and mentioned by several in our sample. Rennie *et al.* noted the epistemic problems of this term in the cancer field, such as lack of a non-arbitrary means of determining how long someone can go without signs of disease to be considered functionally cured.¹⁰

“Remission” is a scary word for some, whereas the term “cure” is inspiring. It is useful for attracting interest to the field, be it financial, scientific, or community based. However, “cure” itself is a loaded term, laden with expectations, hope, and optimism. Some have used the term “durable suppression” when describing a functional cure. Anthony Fauci, Director of the United States National Institute of

Allergy and Infectious Disease, has suggested talking about “overcoming HIV persistence” or “managing HIV persistence.”^{37,38} Management of HIV persistence may be perceived as less emotionally laden, and it more accurately describes the full range of research in this field. It may also set more realistic expectations about near-term progress. Concerns have also been raised about the word “cure” leading PLWHIV to assume more risk than they otherwise would, and the possibility that PLWHIV would mistakenly believe that early stage studies are curative when they are not if the word “cure” is used in association with research.^{21,39} Moving forward, more neutral language may help address some of these concerns. The context will likely matter. For example, in recruitment materials, study names, and informed consent documents, using more descriptive terms that accurately capture the mechanisms being studied, rather than using the term “cure,” may be desirable; whereas “cure” may be quite an appropriate word to use in advocacy and funding contexts.

Despite many perceived benefits of a potential cure for HIV infection, PLWHIV today can manage their disease with antiretroviral medications that are more potent, less prone to resistance, and formulated in easier to tolerate regimens than ever before. The risks of these medications have been well described.² Potential HIV cure study participants will need to carefully weigh the risks, both known and unknown, to their physical and emotional well-being that could come from these new interventions, against the known and unknown risks and burdens of ART.³⁹ Many individuals may perceive the trade-offs as risks that are not worth taking. Researchers need to be diligent in assuring that potential study participants fully understand the risks of participation and that the informed consent process is thorough and implemented diligently.^{39,40}

Finally, as some focus group participants mentioned, the notion of being cured does introduce challenges to a deeply embedded identity—being an HIV-positive person—that has had

TABLE 5. RECOMMENDATIONS FOR RESEARCHERS

Language	Avoid use of “sterilizing.” Use “eradicating” or “eliminating” instead. Avoid use of “functional cure” and “remission.” Use terms such as “durable or sustained suppression.” Be careful and thoughtful using the term “cure” and the appropriateness of the context in which it is used. Consider terms such as “managing HIV persistence.”
Social science research	Provide people living with HIV information about current methodologies being pursued in search of a cure. Then explore their attitudes toward these methodologies. Use social science research to assist with guiding biomedical investment priorities. Consider prioritizing strategies that could potentially lead to viral eradication or elimination. Be mindful of potential psychological and social impacts for individuals participating in HIV cure research. Explore ways to help manage these.
Clinical studies	Incorporate acceptability and other social science research into actual HIV cure clinical studies.
Future social science research questions	When is it acceptable and ethical to implement treatment interruptions and how? How can we best avoid curative misperception? How do historical, policy, and other contextual factors impact stakeholder perceptions of HIV cure research? How should potential transmissibility during ATIs be addressed in differently resourced settings? What factors affect perceptions of trust between potential study participants and researchers? How do PLWHIV perceive specific cure interventions? What are the best ways to communicate HIV cure research risks, benefits, and realities? What are PLWHIV perceptions of current HIV cure research risks, benefits, and realities? How do PLWHIV assess risk/benefit trade-offs for trial participation of specific cure-associated methodologies?

PLWHIV, people living with HIV; ATI, analytic treatment interruption.

strong currency in the HIV response, including being codified in such policies as the Denver Principles, Greater Involvement of People Living with HIV, and Meaningful Involvement of PLWHIV/AIDS, which govern many global programs. What it means to lose, or with some cure strategies, experience fluidity with a salient identity is worthy of further investigation.

See Table 5 for a summary of recommendations.

Limitations

This was a qualitative study of a diverse group of PLWHIV conducted at only four U.S. sites. This study was a community participatory project, and each site recruited study participants locally. Focus groups were of variable sizes and most participants were not enrolled in, and knew little about, HIV cure studies. The sample may overly represent individuals with an interest in HIV cure research. We did not compare the data among the different groups or conduct member checking where findings are shared with participants to elicit feedback. Some focus groups were specific to particular populations affected by HIV, such as women, gay men of color, and long-term survivors; whereas others were more demographically mixed. It was not possible to assess thematic or data saturation since the number of FGDs was determined by our study budget and time constraints for implementation.

Other limitations were inherent to the focus group methodology, such as group dynamics and the challenge of keeping focus groups focused. The discussions may not reflect each individual's concerns. Given the nature of the discussions, respondents sometimes spoke on top of each other, and some passages were indecipherable during the transcription phase. Although some comments may have been lost, we believe that we captured the key essence and passages regarding PLWHIV's perceptions of HIV cure-related research. Transcripts did not indicate the demographics of individual speakers. Future research may be served by more specific understandings of the concerns of particular subgroups of PLWHIV.

Focus group participants shared their thoughts about the concept of an HIV cure. Although we provided focus group participants with an IRB-approved project fact sheet, they were not provided with details about specific interventions under study, nor were most participants knowledgeable about them. Without knowing what types of interventions a cure might consist of, potential side effects, other risks, potential efficacy, and potential durability, it is difficult for people to share perceptions grounded in actuality. We recommend that future social sciences studies incorporate specific information about HIV cure-related research before soliciting opinions of respondents about this complex body of work. Exploration of the acceptability of specific curative modalities under investigation, of potential study procedures, and of more diverse groups of PLWHIV in a variety of global settings is also warranted. This would be consistent with the FDA's initiative to bring the voices of PLWHIV to the forefront of the HIV cure research agenda.⁴¹

Conclusion

FGDs conducted at four U.S. cure clinical research sites provide useful information about the general perceptions of HIV cure-related research among PLWHIV. Importantly, our study brings the voice of PLWHIV to the forefront of the HIV cure research agenda. Based on the findings from this formative research, there is great interest among PLWHIV in the United

States for an eradicating HIV cure, along with concerns about potential harms of cure methodologies, and of unpredictable and possibly unmanageable viral rebound if HIV remains in the body. Cure has powerful meaning beyond the biomedical domain. More resources will need to be invested to inform PLWHIV and engage in meaningful dialogue with communities about the realities of potential cure methodologies and their risks and benefits. Careful management regarding expectations associated with HIV cure research will be essential, and attention to language used to describe HIV cure studies will be of paramount importance.⁴² Further social science research must be conducted alongside these educational efforts, and concurrently with biomedical research to assure that there will be a demand for the interventions that scientists develop.

Acknowledgments

The authors would like to thank the study participants, the Delaney AIDS Research Enterprise (DARE—U19 AI096109), defeatHIV (U19 AI096111 and UM1 AI126623), and Collaboratory of AIDS Researchers for Eradication (CARE—U19 AI096113) Community Advisory Boards. This work was funded by the National Martin Delaney Community Advisory Board, under the DARE—U19 AI096109 grant. The authors also thank Michael Louella, Tranisha Arzah, Manuel Venegas, and Bill Hall for assisting with the Seattle, WA, focus groups. They are grateful to Faith Landsman (UCLA) and Brian Risley (So Cal Men's Medical Group) for their assistance with the Los Angeles, LA, group. They thank Andy Kaytes for his assistance with the San Diego, CA, focus groups. They also thank Virginia Mitchell and Allison Mathews for their assistance with two of the Durham, NC, focus groups.

Author Disclosure Statement

No competing financial interestsexist.

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