What Would an HIV Cure Mean to You? Qualitative Analysis from a Crowdsourcing Contest in Guangzhou, China

Alice Zhang,^{1,2} Xin Pan,¹ Feng Wu,^{1,3} Yang Zhao,² Fengyu Hu,¹ Linghua Li,⁴
Weiping Cai,⁴ and Joseph D. Tucker^{2,5}

Abstract

Much HIV cure social science research has focused on high-income countries. Local key population perspectives, especially from people living with HIV (PLHIV), are needed in low- and middle-income countries. We organized an open contest soliciting responses from key populations, including PLHIV, about what a cure would mean in their lives. Tailored in-person events and social media were used to engage PLHIV, men who have sex with men (MSM), people who inject drugs, and local residents. We received 471 contributions over 4 months. Our thematic analysis showed that many people perceived that a cure would sterilize HIV and bring about new life for PLHIV. Many individuals believed a cure would decrease PLHIV discrimination and many MSM perceived a cure would decrease MSM discrimination. Some participants noted that a cure could help improve interpersonal relations, particularly with families and partners. Many individuals envisioned HIV cure as a panacea to bring about social stability. Some participants also anticipated changes in attitudes toward sex that may result in increased condomless sex. Our findings suggest a continued need for careful management of patient expectations and community engagement.

Keywords: HIV, cure, meaning, crowdsourcing, China

Introduction

TEN YEARS AGO, TIMOTHY BROWN received a stem cell transplant that cured his HIV infection.¹ This is the only known case of a sterilizing HIV cure or complete eradication of the HIV from the body. However, HIV cure research has progressed, and there are several individuals able to control the virus after early antiretroviral therapy (ART) was stopped.² Long-term HIV remission, characterized by an undetectable viral load in the absence of ART, will likely be achieved before a sterilizing HIV cure.³ The search for a HIV cure is now a global priority,⁴ with remission trials in low- and middle-income countries (LMIC), such as China, Brazil, and Thailand.⁵

Previous cure social science research has focused on experts and highly engaged individuals in high-income countries.^{6–8} The limited HIV cure social science research in LMIC has

focused on in-depth interviews with stakeholders, including people who inject drugs (PWID) and people living with HIV (PLHIV).^{9–12} As HIV cure research advances, there is an increasing need for community engagement. Community engagement is the process of empowering people to become actively involved in defining and influencing issues that concern them.¹³ Community engagement within HIV cure research can encourage ethical trial participation,^{14,15} promote post-trial access,¹⁶ and elicit perceptions of cure from patients and the community.¹⁷ Community perceptions of the meaning of an HIV cure may impact PLHIV decision-making and ultimately influence HIV cure implementation.¹⁶ Further research to elicit community perspectives on HIV cure is needed in LMIC settings.

Crowdsourcing may be a useful method to elicit community perspectives on HIV cure research.^{18–20} Crowdsourcing solicits contributions from a group and then shares these

¹School of Medicine, University of Maryland-Baltimore, Baltimore, Maryland.

²University of North Carolina Project-China, Guangzhou, China.

³Center for Medical Anthropology and Behavioral Health, School of Anthropology and Sociology, Sun Yat-sen University, Guangzhou, China.

⁴Department of Infectious Diseases, Guangzhou Eighth People's Hospital, Guangzhou Medical University, Guangzhou, China.

⁵Institute of Global Health and Infectious Diseases, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.

contributions with the public.²¹ Previous public health interventions have used crowdsourcing to promote sexual health,²² sanitation,²³ and cardiovascular health.²⁴ Furthermore, crowdsourcing contests can foster inclusivity and incorporate perspectives from local subpopulations, such as PLHIV.²⁵

Given the importance of identifying community perceptions of cure and the potential for crowdsourcing contests to provide inclusive community feedback, we sought to understand the perception of an HIV cure by crowdsourcing contributions from key populations and others. Our crowdsourcing contest was held in Guangzhou, a Chinese city with ongoing HIV cure trials.⁵ The contest successfully solicited entries from MSM, PWID, PLHIV, and local residents. The purpose of this study was to examine text entries submitted to a crowdsourcing contest on the meaning of an HIV cure.

Materials and Methods

Study setting and participants

We organized a crowdsourcing contest in Guangzhou, China that solicited contributions in response to the question, “What would an HIV cure mean to you?” We solicited contributions from key populations, which included MSM, PWID, PLHIV, as well as local residents (i.e., university students and other local individuals). The crowdsourcing contest took place over 18 weeks, from November 2016 to March 2017. We accepted contributions online (through social media apps and email), as well as in-person at community events. Those who submitted contributions could choose a participation prize of either a small item worth less than 1 USD (i.e., hand cream, tissues, toothbrush) or a raffle entry for an iPad Mini 4 (1 in 300 chance of winning).

Contributions were accepted in text or image format. To promote participation and encourage frankness in the contributions, we did not collect any demographics, such as age, sexual orientation, or HIV status. Contributions were also anonymous. However, for the online contributions, if participants wished to enter the raffle, they were required to provide their name and contact information. Some participants also voluntarily included their names on their contributions during in-person events.

In-person events were tailored based on the recommendations of our partner community organizations and representatives from key populations. At all in-person events, pamphlets were handed out with educational material on the current state of HIV cure research (Supplementary Figure S1; Supplementary Data are available online at www.liebertpub.com/aid). We also provided additional materials emphasizing HIV prevention and treatment, as well as the contact information of the local HIV testing and treatment center (Guangzhou Eighth People's Hospital). Locals fluent in Cantonese and Mandarin were available at in-person events to assist illiterate community members in writing down their responses. Details about each event are included in Supplementary Data.

Data analysis

Two researchers independently coded the data using MAXQDA (Version 12, Berlin, Germany). All entries were transcribed, translated into English, and analyzed in English. Based on grounded theory,²⁶ thematic analysis was used to identify themes on how key populations and others perceived

an HIV cure and its potential impact on their lives. Inductive analysis was used to identify new themes in the data. When coding was complete, discrepancies were addressed and resolved. Themes were then generated based on the codes and refined through multiple reviews of the data set. All identifying information was redacted before coding, and all analyses were performed on aggregated deidentified data that were generated by the crowdsourcing contest. The qualitative analysis of our study was approved by the University of North Carolina at Chapel Hill Institutional Review Board (IRB) and Guangzhou Eighth People's Hospital IRB.

Results

Participant characteristics

We received 471 contributions over 4 months. Characteristics of these contributions are described in Table 1. Thirteen individuals included their names on their contest entries. Nearly all contributions (468) were texts, and three were images. Text contributions ranged from two Chinese characters to two pages of text, with most being a few sentences. Additional original quotations are available in Supplementary Table S1. In addition, the majority of contributions were from in-person events (452) compared to online contributions (19). Among in-person contributions, we received 242 from community venues: 64 from MSM community events, 53 from methadone clinics, and 93 from the HIV clinic (Figs. 1 and 2).

Perception of HIV cure

Contributions from our crowdsourcing contest suggest that many individuals perceived that a cure would be a sterilizing cure that removes all traces of HIV. Based on this assumption, many participants shared their perceptions of what an HIV cure would look like. These perceptions were often

TABLE 1. CHARACTERISTICS OF CONTRIBUTIONS TO HIV CURE CONTEST IN GUANGZHOU, CHINA, 2016–2017 (N=471)

	Number (Percentage)
Targeted populations	
Men who have sex with men	64 (14%)
People who inject drugs	53 (11%)
People living with HIV	93 (20%)
Local residents ^a	261 (55%)
Anonymity of contribution	
Anonymous	458 (97%)
Non-anonymous ^b	13 (3%)
Method of contribution	
In-person	452 (96%)
Online	19 (4%)
Contribution format	
Text responses	468 (99%)
Images	3 (1%)

^aContributions from this population were obtained through in-person community events held at public venues and universities and through social media apps and email.

^bParticipants who submitted contributions online were eligible for the raffle prize if they provided their names and contact information. In addition, during the in-person events, some participants voluntarily included their names on their submissions.

FIG. 2. Word cloud of responses from participants. Frequency of usage represented by word size, created by Alice Zhang and Yang Zhao through www.tagxedo.com

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framed in terms of the impact on PLHIV and mainly focused on sterilization, rebirth, and a return to normalcy.

Cure as sterilization. The perception that a cure would sterilize HIV in previously infected individuals was common. Some responses directly mentioned that the HIV virus could be eliminated from their systems. Other responses were framed in terms of the effect on HIV community. One participant stated, “[there will not be] any more people with AIDS,” while another said, “The HIV community will disappear.”

Some participants anticipated that with a cure, many of the symbols and awareness efforts associated with HIV would be transformed. Participants from community events wrote “[HIV cure] means the red ribbon can disappear.” These responses suggest the belief that not only would those currently living with HIV be cured but also there would not be any new infections.

Cure as rebirth. Second, many contributions mentioned that a cure would bring “rebirth” or “new life.” However, most participants did not elaborate on what this meant. While some participants mentioned that the change could apply to anyone, most envisioned that PLHIV would benefit from a new life. As one online contributor described, “a cure will be accompanied by tears and relief, every patient is thirsty for the rebirth.”

Some PLHIV also agreed that their life would begin anew with a cure, and one participant even looked forward to his potential date of cure as a new birth date. But while most eagerly anticipated the arrival of a new life without HIV, not all were enthusiastic. One participant wrote:

“[HIV cure] would mean a loss—once you get used to bearing all of this and have plans for all of this, if there is a cure, you’ll be at a loss. If my current plans and habits are broken, would I still be myself? Discipline, maturity, and deep depression are the labels that will be broken. Will I start a new life or will I screw it up? I overcame it the first time, maybe the second time I will smile at it, or perhaps I’ll be beyond redemption.”

This participant also recognized that a cure had the potential of giving him a new life, but the prospect of a new life was daunting because he had finally come to terms with living with HIV and developed habits to help him cope. As a result, he expressed hesitation at the thought of a new life, because it would require him to readjust his life again.

Cure as a return to normalcy

Other contributions mentioned that a cure would allow PLHIV to return to a normal life. Some thought cured individuals would no longer be abnormal, returning them to their previous state and becoming accepted in society again. One individual from the methadone clinic commented, “[patients] would be like normal people, integrating into society—this big family.” PLHIV also perceived that a cure would allow them to resume an identity like everyone else, and one participant from the HIV clinic stated, “[cure] means we are truly normal people.” Based on three main perceptions of HIV cure, our findings highlighted four themes as shown in Table 2.

Discrimination and stigma

Based on three main perceptions of the meaning of an HIV cure, participants shared what an HIV cure would mean for

TABLE 2. FOUR MAIN THEMES FROM THE RESPONSES TO “WHAT WOULD AN HIV CURE MEAN TO YOU?”

What would an HIV cure mean to you?
Discrimination and stigma (1) Impact on PLHIV (2) Impact on MSM
Improved interpersonal relations (1) Relation between PLHIV and the general public (2) Impact on family (3) Romantic relationships
Social stability The words “more beautiful,” “happier,” and “sunshine” were used to suggest that there would be reduced conflict in the event of a cure.
Sexual attitudes and perceived risk (1) More liberal attitudes toward sexual behaviors (2) Perception of HIV risk

MSM, men who have sex with men; PLHIV, people living with HIV.

their own lives. Ninety individuals stated that an HIV cure would impact discrimination and stigma in some way, and most anticipated a reduction in or elimination of stigma. These responses ranged from short entries with a few Chinese characters to longer entries with a thorough discussion.

Contributions solicited from community events, including the HIV clinic, overwhelmingly indicated that PLHIV would no longer receive as much discrimination. Similarly, contributions solicited from MSM community events indicated that a cure might reduce or eliminate discrimination toward MSM. Those who were MSM living with HIV focused on HIV discrimination and stigma.

Impact on PLHIV. Many contributions referenced the discrimination that PLHIV currently face in workplaces, hospitals, and other everyday settings. Respondents described discrimination in the form of overt policies, refusal of services, or lack of accommodation. Some contributions from PLHIV mentioned that the threat of stigmatization and discrimination gave them a significant psychological burden and caused them to alter their behaviors. With a cure, they expressed hope that others would no longer view PLHIV differently or discriminate against them, resulting in equal rights and greater peace of mind.

“[Cure] means having equal rights to get medical treatment and employment. Cure means having equal rights to be a human being, regaining respect, no longer having to hide in shadows.”

However, not all were optimistic about a cure’s ability to eliminate discrimination. One individual noted that discrimination toward PLHIV has deeper roots that would need to be addressed.

“Even if [HIV] can be cured, people will still have worries of ‘What if [PLHIV] are not completely cured? What if they have relapses?’ [...] For me, what is more important in AIDS

cure is the psychological cure of people living with AIDS, and this requires the joint effort of the community. Otherwise, even if AIDS can be physically cured, isolation and discrimination would still be able to 'kill' the people who are physiologically cured of AIDS."

Impact on MSM. Contributions from MSM community events were the only ones that mentioned the cure's potential to reduce discrimination and stigma toward MSM. These contributors noted the association between homosexuality and HIV in China, especially in recent years, and the resulting stigma it has created for the MSM population.

"I think that HIV is an ordinary disease, not anything special. I do not want to equate HIV with homosexuality, even though they are related. I think society naturally equates HIV with homosexuality and treats them with the same horror."

Individuals were hopeful that a cure would remove the association and perhaps have an impact on homophobic attitudes.

"HIV cure can free MSM from HIV stigma and discrimination and let society recognize this group."

Improved interpersonal relations

A large number of contributions (115 out of 471) also mentioned that a cure would improve interpersonal relations. These contributions mentioned the following three main types of relationships that would be affected: those between PLHIV and the general public, family relations, and romantic relationships.

Relationships between PLHIV and the general public. Many individuals suggested that reduction of stigma toward PLHIV would create greater respect, reduce suspicion, and ultimately allow PLHIV to be accepted by the general public. One participant noted: "AIDS cure can give patients social recognition and approval." PLHIV also expressed hope that social interactions could become more convenient and that they could avoid the fear of disclosure and embarrassment when interacting with others.

Impact on family. Many contributions mentioned the impact of a cure on family relations. Contributions from community events and methadone clinics suggested that a cure would generally bring greater family happiness and harmony. Some PLHIV mentioned that a cure would relieve family members of some of their burdens and worries.

"Good for family members. [...] If it can be cured, my family members will be a lot better psychologically. Right now their current status is that they still can't believe what's happening."

Contributions from the HIV clinic and MSM community events also mentioned that a cure would allow individuals to be healthier and live longer. As a result, individuals would be able to fulfill duties in taking care of their parents and children.

Romantic relationships. Individuals from the HIV clinic and MSM community events also mentioned the impact of cure on romantic relationships. Some PLHIV hoped that a cure would help them find a wife and also allow them to have children, since they are currently afraid of transmitting HIV to their children.

Many MSM focused on an HIV cure's impact on romantic relationships. They expressed the sentiment that HIV currently prevents them from getting into long-term and stable relationships because there is the fear of infection. They stated that the constant threat of HIV makes them unable to think of the future and to be with the one they love. Some stated that as a result, their relationships consist solely of online dating and having sex with strangers.

"We do not even have stable sexual partners or stable sexual relationships. Not even those things can be achieved, let alone stable love. Nobody likes having sex with strangers, promiscuity, or finding different partners on dating apps. HIV is like homosexuality's stealth bomb: you do not know when it will explode."

Some expressed the hope that with a cure, there would be more opportunities for stable and long-term relationships for MSM.

Social stability

Related to improved interpersonal relations, one theme that emerged was social stability. The phrases "harmonious society" and "world peace" appeared in 78 contributions, particularly in those submitted by individuals from community events. One individual from the community event wrote, "World has love, World without AIDS."

These contributions suggest that there would be reduced conflict in the event of a cure. One reason cited for the current state of conflict was the purported acts of "revenge" by PLHIV. A few individuals mentioned the "cold violence" brought by PLHIV who sought to purposefully infect others with HIV. Hence, some believed a cure would eliminate these acts, thereby reducing fear and conflict in society. One individual noted, "Groups of AIDS patients may have extreme problems from hating others and society because of their own HIV-positive status. So, HIV cure's biggest contribution is societal harmony." Similarly, there was also the depiction of a friendly and equal society in which all individuals contribute, with greater security and peace of mind for everyone. The words "more beautiful," "happier," and "sunshine" were used often in these contributions.

Sexual attitudes and perceived HIV risk

Many individuals anticipated that a sterilizing cure would change sexual behaviors.

More liberal attitudes toward sexual behavior. Nineteen individuals believed that people would engage in more sex but decrease condom use. One participant stated, "I will relax my restrictions on sex and have more sex with strangers." For some, having more liberal sexual attitudes and behaviors was seen as a generally positive change, calling it "an advancement for society" or a "sexual liberation era." For others, these anticipated changes were seen negatively, with some describing the behaviors to be "unscrupulous" and "indulgent."

"If AIDS can be cured, possibly people's concerns about sex will decrease a lot, and sex will be more liberal. Liberal sex is not a very good thing. People may visit prostitutes in an uncontrolled manner, which may impact family feelings, cause divorce rates to increase, and infection rate to increase."

TABLE 3. THE TOP 3 THEMES FROM RESPONSES TO THE QUESTION “WHAT WOULD AN HIV CURE MEAN TO YOU” FROM FOUR DIFFERENT GROUPS

Groups	Top 3 themes		
MSM	HIV and MSM stigma, 28%	Sexual risk, 27%	Romantic relationship, 14%
PWID	Social stability, 28%	Health, 19%	Family, 15%
PLHIV	Family, 30%	Mental stress, 17%	Health, 16%
Local residents	Social stability, 23%	HIV stigma, 17%	Sexual risk, 12%

PWID, people who inject drugs.

Maybe this is a little alarming, but this harm cannot be easily ignored.”

Some hoped a cure would not occur so that the fear of HIV infection would prevent certain sexual behaviors, such as having more casual sex or sex with strangers.

Perception of HIV risk. The anticipated changes in sexual behaviors suggest that some individuals may perceive the risk of HIV infection differently in the event of a cure. Eighteen individuals stated that there would be greater security and safety in their sexual lives because they did not need to worry about HIV infection. One individual noted, “[Cure] means one can be more casual about having sex without being afraid of getting infected.” There was also the perception that the risk of infection would decrease or disappear with a cure. One individual from a community event wrote, “[HIV cure means] we have no chance of getting HIV.” Consequently, some individuals stated that they could anticipate people acting more “carelessly” and not taking the proper preventive measures. However, some individuals stressed that despite a cure, there was a continued need for protection against HIV and other STDs.

“But of course, if there is a cure for AIDS that does not mean one can just have sex unscrupulously...You still need to give yourself and the other person some protection. In short, if you want to take off your pants, you must wear a condom.”

Thus, many individuals anticipated that an HIV cure would decrease perceptions of HIV risk in their sexual lives.

Discussion

In our crowdsourcing contest conducted with key populations and local residents in Guangzhou, China, many participants stated that a potential HIV cure would have a substantial impact on their lives and within society. These changes include a reduction in HIV stigma, improved interpersonal relations, greater social stability, and increased risky sexual behaviors due to decreased perception of risk of HIV infection. Previous qualitative research on HIV cure has generally focused on the perceptions of local PLHIV and experts.^{6,9,12} While these are important stakeholders in cure research, there are many others who will also be affected by a potential cure. This study extends the literature by examining perceptions of HIV cure in an LMIC setting and evaluating crowdsourced responses using qualitative methods.

Our community crowdsourcing data revealed three key messages. First, contributions from our crowdsourcing contest suggested that individuals believed that an HIV cure would be sterilizing. Previous qualitative research in Guangzhou highlighted PLHIV’s perceptions that cure would bring

hope,^{9,10} but did not clarify further. The perception of a cure as sterilizing may impact current behavior in unpredictable ways. Some communities may adhere to healthy behaviors and support ongoing research in the hopes of obtaining a sterilizing cure, while others may withdraw support for ongoing research in anything less than a sterilizing cure. Given that HIV remission is more likely than a sterilizing cure,³ our results suggest a need to improve public education about ongoing HIV remission research.²⁷ The challenge of appropriately framing expectations extends beyond China and highlights the need for thoughtful education efforts.^{11,12}

Second, the diversity of themes suggested that an HIV cure may have divergent meanings among PLHIV and other individuals.²⁸ The top 3 responses from four groups (MSM, PWID, PLHIV, and local residents) are shown in Table 3. As Table 3 illustrates, different communities perceived different types and magnitudes of concern toward the meanings of HIV cure. These differences may represent different priorities based on the physical, psychological, and social challenges each group currently faces. For example, MSM were the only group to mention how an HIV cure could impact MSM stigma. Local residents had the largest variety of responses, with few emerging themes. These aspirations highlight the need for inclusive community engagement and consideration of divergent priorities among subpopulations. Previous research has focused on PLHIV,^{6–8,10} but it is also important to engage other key affected populations and encourage them to share their perspectives.

Finally, a considerable number of individuals from key populations anticipated that a cure may lead to riskier sexual behavior. The potential for decreased risk perception has been noted with many HIV prevention and treatment interventions,²⁹ including pre-exposure prophylaxis (PrEP).³⁰ In some communities, the advent and increased accessibility of ART has led to a decreased perception of HIV risk accompanied by a reduction in condom usage and an increase in sexual partners.^{31,32} However, other studies have found that in some settings, male circumcision and PrEP are not associated with risky sexual behaviors.^{33,34} Our data suggest that public health messaging will be an important component of a comprehensive HIV cure strategy.

Our study has several limitations. First, due to the nature of soliciting contributions for a crowdsourcing contest, we were unable to probe for more details from any contributor. We did not collect any identifying characteristics from participants to preserve anonymity and promote participation. Second, we only held contests at a few locations, and we did not reach populations throughout all regions of the city. Third, we gave all participants educational information about HIV cure research at the time they submitted responses. Thus, we may have inadvertently influenced their perceptions (Supplementary Data).

Nonetheless, despite these limitations, our crowdsourcing contest was able to solicit over 470 contributions from a broad cross-section of the community in Guangzhou. Our contest was accessible in many ways, either through in-person events or social media. We had both Cantonese and Mandarin speakers at our in-person events to assist illiterate community members in writing down their responses. In addition, our partnerships with community organizations were crucial in tailoring each event to the population at hand. Thus, our crowdsourcing contest was able to solicit a diverse range of perspectives about the meaning of an HIV cure.

Our findings have implications for HIV cure clinical research and community engagement. We found diverse perspectives about a potential HIV cure among key populations. For ongoing HIV cure research, this suggests a continued need for careful management of patient expectations and community input. Our crowdsourcing method could be useful as a way to solicit community input on clinical HIV cure trials. Moreover, our findings emphasize the importance of maintaining and extending existing programs to increase HIV cure literacy and community awareness.³⁵

Conclusions

Our research study demonstrates that community perceptions of HIV cure are divergent. Given the uneven march of scientific progress, this underlines the importance of iterative HIV cure community engagement activities. Crowdsourcing could be a useful mechanism to provide transparent inclusive feedback on HIV programs and trials.

Acknowledgments

The authors thank Guangzhou Eighth People's Hospital, UNC Project-China, and Social Entrepreneurship for Sexual Health (SESH) Global for their administrative support. The authors also thank Katherine Li for her research assistance. Funding details: this work was supported by the National Institute of Health NIAID under grant #1R01A108366-01 and by the Doris Duke Charitable Foundation through a grant supporting the Doris Duke International Clinical Research Fellows Program at the University of North Carolina at Chapel Hill.

Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

Joseph D. Tucker
University of North Carolina Project-China
No. 2 Lujing Road
Guangzhou 510095
China

E-mail: jdtucker@med.unc.edu