'I can coexist with HIV': a qualitative study of perceptions of HIV cure among people living with HIV in Guangzhou, China

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Abstract

Little is known about perceptions of HIV cure among people living with HIV (PLHIV), despite them being crucial stakeholders in ongoing HIV cure research. A qualitative research study was conducted in Guangzhou, China, to explore the perceptions of HIV cure among PLHIV in relation to their views on HIV treatment, stigma and social identity. We conducted in-depth interviews with 22 PLHIV from September 2014 to June 2015. Our qualitative data revealed three major themes: (1) Representations of HIV cure: PLHIV generally thought HIV cure was distant from them; (2) Possibility of HIV cure: ideas about the possibility of HIV cure ranged from optimism to scepticism and pessimism; and (3) Life without HIV cure: some participants had adjusted well to the chronic condition of HIV and ART adherence. Although some PLHIV looked forward to HIV being cured, most of the PLHIV in our study had little interest in it. On the contrary, many felt it is more important and realistic to have access to better ART medication and more education for the general public to decrease HIV stigma today rather than develop a cure for tomorrow.

Keywords: HIV cure, perceptions, qualitative research, PLHIV, China

Introduction

People living with HIV (PLHIV) are important HIV cure research stakeholders [1]. However, their voices are underrepresented in the current literature [2]. Little is known about how PLHIV perceive HIV cure in relation to antiretroviral treatment (ART) adherence, stigma and their daily lives. PLHIV's perceptions of HIV cure may influence clinical trial participation [3–5], HIV treatment adherence [2] and psychosocial well-being [6,7].

PLHIV's perceptions of HIV cure are influenced by many factors. On the global scale, the triumphs and failures of HIV cure research in recent years, as shown in the cases of Timothy Brown (otherwise known as 'the Berlin patient') [8], the Mississippi Baby [9,10], the Boston patients [11] and the Visconti cohort [12], have complicated public perception of HIV cure. In addition, ambiguity in the scientific community about how to describe 'cure', using terms like 'sterilising cure', 'functional cure' [13] or 'remission' [14], may add to confusion about what might be expected. It is unknown how PLHIV perceive these medical terms, particularly in non-English-speaking, middle-income countries, like China.

On the national scale, China has a strong emphasis on HIV cure, like high-income countries [15]. Compared to other low- and middle-income countries, China has far more HIV cure research activities [16–18]. Historically, the HIV/AIDS epidemic in China dates to the late 1980s [19], but it was not until 2004 that the Chinese government provided free ART under the 'Four Frees and One Care' policy [20]. By the end of 2011, there were 780,000 people estimated to be living with HIV in China [21] and 126,448 of them were receiving ARV treatment, which accounted for 76.1% of HIV-infected adults and children who met the treatment criteria [22].

In addition, similar to many other places around the world, China still has a high degree of HIV stigmatisation and discrimination [23], not only in terms of individual and social discrimination, but

*Corresponding author: Joseph D. Tucker, University of North Carolina Chapel Hill Project-China, No. 2 Lujing Road, Guangzhou, China, 510095 Email: jdtucker@med.unc.edu also institutionalised discrimination. For example, PLHIV are still ineligible to be hired as civil servants [22]. These international, national, historical and social factors combined have repercussions for PLHIV's current perceptions of HIV cure, which have yet to be explored.

In this context, our qualitative study explores perceptions of HIV cure among PLHIV in China: How do they think about HIV cure in relation to ART and their HIV identity in society? We attempt to fill the gap in the literature by examining the perceptions, concerns and expectations of HIV cure from the perspective of PLHIV. The main objective of this study is to bring the voices of PLHIV into the scientific design and interventions for HIV cure research and to provide evidence for promotion of patient-centred research.

Methods

Study design

We conducted a qualitative study to explore perceptions of HIV cure among PLHIV at the largest infectious diseases hospital in Guangzhou, from September 2014 to June 2015.

Study setting and participants

Guangzhou is the third largest city in China with a population over 13 million people. The average *per capita* annual income in Guangzhou was approximately 12,609 US\$ in 2015 [24]. The average educational level in Guangzhou is a three-year bachelor's degree, which makes it the fourth most educated among major Chinese cities [25]. In 2014, the total number of PLHIV in Guangzhou was estimated to be 17,861 [26]. We recruited PLHIV who were 18 years or older from the outpatient clinic of the hospital through convenience sampling. The PLHIV were approached following their clinical visit. At the time of our study, there were no clinical trials for HIV cure in Guangzhou.

Ethics statement

The Institutional Review Boards at the Guangzhou Eighth People's Hospital and the University of North Carolina at Chapel Hill

approved this study. All participants provided verbal informed consent because the study was determined minimal risk. Each participant was given a phone card worth 50 RMB (8 US\$) for participating.

Data collection

Semi-structured, in-depth interviews (lasting between 30 and 60 minutes) with PLHIV were conducted in a private room in the hospital or in a quiet area of a nearby park. Nineteen interviews were audio recorded when permission was obtained from participants. Three participants refused audio recording, but accepted note-taking by the researcher. Interviews included questions collecting basic demographic and clinical data, information about participants' conception and knowledge of HIV cure, and ideas about the relationship between their current life and HIV cure (see Appendix). The interviews were open-ended. All of the interviews were conducted in Mandarin Chinese by two researchers who are both native Mandarin speakers.

Data analysis

Audio-recorded interviews were transcribed verbatim from recordings in Mandarin Chinese. One researcher reviewed the transcripts for completeness and accuracy by reviewing the audio recording. The potential identifiers were redacted from transcription and detailed written notes to protect participants' identities. Data were imported to MAXQDA (Version 7) for analysis. Data analysis was conducted in Mandarin Chinese. One researcher performed the initial coding based on grounded theory [27], the other researcher examined the coded texts to identify emerging themes. The two researchers cross-examined the themes. Quotations supporting the themes were translated into English at the time of manuscript writing.

Results

A total of 22 PLHIV were recruited for in-depth interviews. The majority of PLHIV who participated in our research were between 20 and 50 years old; more than half of them had received an undergraduate education; participants had a median income of 27,000 US\$ (Table 1). Twenty-one out of 22 interview participants were on ART. Our qualitative data analysis revealed three major themes of PLHIV's perceptions of HIV cure: 1) Representations of HIV cure – how PLHIV imagine life after being cured of HIV; 2) Possibility of HIV cure – whether or not HIV cure will happen, how soon it will happen and whether the cure will be accessible to them; and 3) Life without HIV cure – how PLHIV adjust to the chronic condition of HIV and persisting concerns of living with HIV.

Representations of HIV cure

Although HIV cure is a novel scientific concept, the PLHIV we interviewed were able to express their views of a life free of HIV. Their representations of HIV cure can be divided into perceptions of biological reality of cure, preferable forms and duration of cure, and perceptions of the potential impact of cure on physical health and emotional status.

Biological reality of cure

The biological reality of cure refers to PLHIV's perception of how HIV cure can influence the virus in their body. Our respondents indicated that a cure should be complete viral eradication forever, with no virus remaining inside their body. They did not mention or seem to understand the medical distinction between sterilising cure and functional cure. Furthermore, some participants believed the detection of no virus should mean that they did not need to take medication anymore. One participant said: 'No viral detection.

Table 1. Demographic and clinic characteristics of PLHIV (n=22)	
Demographic characteristics	Number
Gender	
Male	14
Female	8
Age	
20–29	2
30–39	8
40-49	8
50–59	1
60–69	2
Missing	1
Education	
Elementary School	1
Junior high school	3
Senior high school	1
Undergraduate	9
Postgraduate	2
Missing	6
Income (US\$/year)	
Median annual income based on eight participants	27,000
Minimum	7,100
Maximum	1,575,000
Marital status	
Married	12
Single	3
Divorced	1
Missing	6
Clinical characteristics	
Length on ARV	
Never	1
Below 1 year	5
1–5 years	8
More than 5 years	3
Missing	5

And you don't need to take any medication. If you need to take medication for a long term, it doesn't mean you are cured.'

Preferred forms and duration of cure

Most participants preferred a cure in the form of a pill, with an injectable cure as the second choice. Some forms of cure, such as chemotherapy analogous to cancer treatment, were deemed completely unacceptable. As for the duration of cure, respondents expected the time to complete viral eradication to be as short as possible.

Impact of cure on the life lived

The strongest feelings regarding HIV cure were revealed when participants described what cure would bring to their lives. In addition to improved health, they felt that cure would bring hope to their lives and, consequently, bring them happiness. A cure would mean not hiding their serostatus and being 'normal', as one participant stated: 'I know my infection will scare other people. So I don't tell most of my relatives and friends. If I can be cured, I won't worry about it. I would be normal. I will be very, very happy.'

Possibility of HIV cure

Ideas about the possibility of HIV cure ranged from optimism to scepticism and pessimism.

Cure optimism

Some participants believed HIV could be cured eventually, as revealed by this participant's statement:

I believe there will be a cure one day. HIV can be cured. But I don't know how long it is going to be. There is no immediate cure when a new disease first appears. If someone can cure HIV, the person should win the Nobel Prize.

Some compared HIV with other chronic diseases, such as diabetes, which they regarded as incurable. Others believed that, in the end, 'a lot of diseases can be cured'.

Cure scepticism

Cure scepticism includes participants' suspicion of cure availability and cure feasibility. Although our respondents would have been happy with a cure, they were also sceptical about whether a cure would be available to them, expressing that an HIV cure may just be a dream and they might not live long enough to see the dream come true. Some participants frequently referred to Timothy Ray Brown, who symbolises both the hope and myth of HIV cure for them. One participant said: 'That (the Berlin patient) has a genetic mutation. The probability is too slim. For me, it is nearly impossible.' Some participants felt HIV cure was far away from them, as they thought a cure might be hidden or inaccessible. For example, one participant said: 'My cousins are in the United States and they are medical researchers. They told me HIV can be cured in the United States.' Another participant stated that a cure for HIV always exists elsewhere, hiding in something we did not know very well, such as traditional Chinese medicine (TCM), which may provide a mysterious cure.

Cure feasibility was represented by participants' concern of cost for a cure. Some felt that a high-tech cure would never be affordable to them, as one participant said:

The Berlin Patient is a dead end for HIV cure research. We are not interested in HIV cure. We just want a better medication. The cost for transplant surgery is very expensive. It is too expensive for people in Africa and China. I am not interested in a cure at all.

Cure pessimism

Finally, there were participants who were pessimistic in general about HIV cure and did not believe HIV could be cured at all. One participant said: 'There is no such thing as HIV cure in the world. Don't you think so?' Another participant thought controlling the virus may be possible but also noted: 'I don't think cure is possible. I feel we can only stabilise the viral load and not let it expand.'

Life without HIV cure

This section describes how PLHIV cope with their current life with HIV infection, ART adherence, emotional distress and stigma associated with HIV, and how these are related to their perceptions of HIV cure.

Accepting the chronic condition of HIV infection

In contrast to the view expressed by some participants, that without cure there is no hope, others expressed that they had adjusted well to the chronic condition of HIV. These individuals were cautious in response to the idea of upcoming clinical trials with 'cure' as a goal. Instead, they emphasised that a positive attitude towards life with HIV infection was more important at the present time than a cure. As one participant said: 'Although it would be better if HIV can be cured, I can accept it as a chronic disease. I have at least a few decades to live, I don't really care if I can be cured right now or not.' Another participant mentioned Magic Johnson as an inspirational example of maintaining a balanced perspective.

Normalising life with HIV treatment

Several participants noted that ART medication adherence is the new normal for them. One participant was diagnosed with HIV in 2005 and has taken traditional Chinese medicine since then. Although she has never been on ART, she has to take TCM every day. She described her life over the past ten years:

My life is almost normal. I don't feel anything obviously different. I only need to take medicine in addition to my daily meals. It is almost the same...I feel I am very accustomed to it (medication). I will take the medicine after meals no matter what. It is like drinking tea.

Positive attitude towards coexistence with HIV

Some participants also emphasised the importance of a positive attitude towards coexisting with HIV. One participant said:

I now live with this virus. My body needs to be in good condition, then I can have a strong immunity, with which I can achieve balance in my life, I can coexist with HIV. If I am troubled by other things and don't eat well, the condition of my body will go down. Then the virus will come to bother me. Then every other disease will follow.

Another participant said that he understood HIV was part of his body, and for this reason, he should live better so he could live longer:

I need to adjust my own mood and imagine I am a healthy man. Now I want to live better. I want to live for three years, five years or ten years. There have been only three decades since the outbreak of the epidemic. I was scared and I wanted to escape from all of this. But HIV is part of my body now. If I escape, I will fail.

Some participants thought HIV cure was an extra bonus, but not something essential in their lives and not something they considered a priority. Other things, such as family and children were more important for them.

Emotional Distress and stigma

Our data show that emotional distress caused by HIV infection was still common. Several respondents expressed that after becoming infected, they lost all hope. One participant said it was 'delusional' to expect a near-normal life expectancy even if someone had good ART adherence. Even ART sometimes has become a symbol of HIV infection and one participant expressed distress over ART adherence itself:

Taking the medication is not a big deal. I can do it. It is fine to take medicine every day for a certain period if I know the

medication can lead to a cure. But taking the medicine everyday endlessly makes me think of HIV. If I don't need to take the medicine, I won't think I am HIV infected.

In addition, HIV stigma is so pervasive that it can even enter into the imagination of a future state of being cured. One participant worried that even after HIV is cured, any trace of HIV inside his body, such as the antibody to HIV, would reveal his former seropositive status. He said: 'As long as I still have antibody, I don't think my identity as HIV infected will change, even though I am cured of HIV.'

Discussion

This study provides an overview of how some PLHIV in China think about HIV cure and cure research, before any were approached with the possibility of participating in a cure trial. Our results demonstrate that PLHIV in China generally perceive HIV cure as a distant possibility, inaccessible and expensive. This finding is consistent with other qualitative research about HIV cure in China among people who inject drugs (PWID) [14]. While there are important differences between the PWID participants and our sample of PLHIV, - notably lived experience of injecting, education level and income - their similar perceptions of HIV cure reinforce the general sense of inaccessibility of HIV cure by people from a variety of backgrounds in China. Perceptions of HIV cure as inaccessible, available only to selected groups and too expensive are not simply pessimistic perceptions. There is a historical precedent not only in China, but also in other resource-limited settings. China did not offer free ART before 2003 [28] and there was a general absence of ART in sub-Saharan Africa in the early decades of the AIDS epidemic [29], whereas ART has been largely available in high-income countries since 1996 [30]. In addition, the perception that HIV cure would be prohibitively expensive resembles the current dilemma of the high cost of drugs curing hepatitis C infection, and how to lower prices to make that cure available to more people [31-33]. This perception of HIV cure further highlights the need to prioritise universal access to an HIV cure in terms of availability, accessibility, acceptability and quality as basic human rights to health [34].

In addition, our data also revealed that some participants were satisfied with their life without HIV cure. For some of them, the chronic condition of HIV infection and ART adherence has become a normal facet of their life. Indeed, one might conclude from our interviews that normalisation of living with HIV makes them less enthusiastic about HIV cure. The normalisation of HIV as a chronic condition has been noted in other studies [35-38], but none of them was conducted before HIV cure became a priority in medical research. In contrast to our findings, a qualitative study of stakeholders' perspectives of HIV cure research in South Africa [7] reported that: 'Participants became tearful and distressed when reminded that a cure was only a possible event in the distant future.' However, those in our study seemed to accept HIV cure as 'far away' without exhibiting the same level of distress. This contrast reveals heterogeneous perceptions of HIV cure and is significant for international medical researchers and funding organisations, as it underlines the importance of understanding local contexts when HIV cure trials are launched. This finding reinforces the necessity of integrating more social science research with biomedical research on HIV cure [39].

As noted in the global literature on stigma and discrimination associated with HIV [23,40,41], our data further suggest that some participants view stigma and discrimination associated with HIV as the biggest concern in their lives, even if a cure may come in the future. Although a previous study projected that an HIV cure

could significantly lessen the stigma associated with HIV [42], our findings indicate that a cure would be valuable only if prior HIV-positive status could remain a secret, as hiding HIV identity from family, friends and society was participants' primary concern. This finding is consistent with the argument regarding the ways that social relationships may influence people's perception of HIV cure [43]. Therefore, our study suggests that even when a cure is available, family-centred interventions are still an important strategy to reduce stereotypes and misconceptions surrounding HIV and to provide potential social support. In the meantime, some of our research participants value better medication and less frequent dosing over any expectation for a cure for HIV. Previous studies show that the pill burden associated with ART has negative impact on ART adherence [44], and poor adherence may result in virologic failure and transmission of the highly resistant virus [45], thus, an HIV cure would eliminate these disadvantages of ART [42]. While an HIV cure might address many of the concerns of PLHIV, it is still intangible and unavailable. Stigma and ART adherence, on the other hand, are tangible forces shaping the current lives of PLHIV. Our research participants stated that it is more urgent and realistic to have access to better medication with less toxicity, perhaps taken less frequently, and to lessen the stigma associated with HIV in society.

There are a number of limitations in this study. First, it is a small qualitative interview study in one urban hospital. As such, its generalisability to other Chinese cities and to rural areas is limited. Second, our research participants were more likely to be taking ARVs than other groups of PLHIV, as they were recruited from the hospital and already had established hospital records. Third, because there were no clinical trials taking place in Guangzhou at the time, our interview questions regarding HIV cure for research participants were hypothetical, with well-known limitations regarding the relationship between perceptions and subsequent behaviours. Finally, we only conducted a one-time interview with each participant. Longitudinal research will be needed to capture the changing perceptions of cure, and its potential harms and benefits.

Conclusions

Our data bring in the voices of PLHIV regarding HIV cure, which provide evidence for patient-centred scientific design and interventions for HIV cure research. Our data suggest that issues surrounding HIV treatment are still considered the highest priority among PLHIV in China. In the meantime, excitement about HIV cure research should not obscure the need to provide better and more kinds of ART, to educate the general public about HIV, and to lessen stigma associated with HIV. In addition, HIV cure researchers should acknowledge the importance of HIV treatment and the widespread scepticism towards cure among PLHIV. Particularly in regard to recruitment for clinical trials, physicians should be honest about the uncertainty of risk and future cost for HIV cure, balancing this transparency with the need to convince potential participants that HIV cure research may lead to something real and valuable, in the future. More importantly, our findings also highlight the heterogeneity of PLHIV's perceptions of the possibility of HIV cure. The contrasting viewpoints from our small sample underlines the centrality of PLHIV in HIV cure research and related activities [2].

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Conflicts of interest

All authors declared no conflicts of interest.

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Appendix. Interview guide for in-depth interview with PLHIV

Categories of the interview questions	Sample questions
Demographic and clinical data	Questions inquiring age, gender, education, income, marriage, length of HIV infection and length on ART
Conception and knowledge of HIV cure	Have you heard about HIV cure? Do you think HIV can be cured? Where did you hear about HIV cure? According to your experience, what is HIV cure?
Current life conditions and ideas about the relationship between their current life and HIV cure	What is the self-comment on the current status of HIV infection? Do you think HIV cure can change your current life? What change do you think HIV cure can bring to your life?