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Exploring the Social Meaning of Curing HIV: A Qualitative Study of People Who Inject Drugs in Guangzhou, China

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Abstract

Our objective was to explore the social meaning of HIV and perceptions of an HIV cure among people who inject drugs (PWID) in Guangzhou, China, which speaks to ethical and resource challenges to development in this field. We conducted a qualitative research study using in-depth interviews. We analyzed interview transcripts from 29 PWID, eight physicians, and three social workers from an outpatient HIV clinic and two methadone maintenance treatment centers. The social meaning of HIV infection and perceptions of an HIV cure reflected patients' relationships with society, health systems, and physicians. First, HIV infection decreased perceived social worth and disrupted peer relationships. The possibility of being cured renewed patient hope for regaining physical well-being and achieving social mobility. However, the existence of a cure may not alter the HIV-related stigma due to its association with stigmatized behaviors and marginalized groups. Second, although stigma was a significant barrier to engagement in health care, hope for a cure may outweigh fears of stigma and enhance linkage to HIV testing and treatment as well as methadone services. A cure may exacerbate perceived health disparities if inaccessible to key affected populations such as PWID. The social implications of an HIV cure among this key affected population may inform the design and implementation of cure clinical trials. Careful management of patient expectations, focusing research on key affected populations, expanding HIV testing and treatment systems, improving access to harm reduction programs, and ensuring post-trial access are important considerations for HIV cure research.

Introduction

IN THE PAST THREE DECADES, the meaning of HIV as an illness has evolved significantly for patients: from facing imminent mortality, to enduring toxic treatment regimens, to now the long-term task of managing a chronic disease and preventing acute complications.¹ Recent cases of HIV-infected individuals who are healthy off antiretroviral treatment (ART)^{2,3} have accelerated research efforts toward a generalizable cure.⁴ The potential transition of HIV from an incurable to curable disease may bring substantial changes to health systems and have unique social and ethical implications.⁵ After all, HIV is as much a profound social issue as a medical one, disrupting social relationships and dispropor-

tionately affecting marginalized populations.⁶ Early clinical trials are studying treatment during acute infection, gene modification to confer innate resistance to HIV, administration of neutralizing antibodies, and therapeutic vaccines.⁴ However, these experiments are limited to proof-of-concept studies bridging animal and human research in order to develop tools and methods for future clinical trials and have no clinical benefit for participants.⁵

In this study, we focused on people who inject drugs (PWID) in Guangzhou, China, a key affected population that bears a significant burden of HIV. There are approximately 1.16 million drug users in China and 6.4% are HIV infected, compared to 0.03% in the general population.⁷⁻⁹ The risk environment theory argues that people who inject drugs are

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susceptible to structural and environmental factors that increase their risk for both substance abuse and other health-related harms, including HIV infection.^{10–12} China, in particular, has the largest population of drug users in the world, and injection drug use accounts for 20% of all new HIV infections.^{9,13} Furthermore, PWID traditionally have very low rates of linkage to HIV care and may face some of the largest barriers to accessing a potential HIV cure.^{14,15} Focusing on PWID was an opportunity to examine relationships between individuals, physicians, health systems, and society.

China is experiencing a rapidly evolving health policy environment with growing political support for harm reduction and scale-up of HIV prevention, testing, and treatment efforts.^{16,17} The emergence of national “champions” encouraged a culture of pragmatic, evidence-based practice that has spurred collaboration across public health, police, and drug sectors.^{16,17} However, HIV continues to hold a powerful cultural meaning in China as the modern-day plague.¹⁸ Fear of infection and death are magnified by its association with stigmatized behaviors,¹⁹ which continue to hinder progress in HIV care. A complex social environment, coupled with rapid change in health policy, provide a unique opportunity to examine social relationships that may be affected by an HIV cure.

Qualitative research has helped define social and structural factors of the HIV epidemic,²⁰ influence program implementation,²¹ and enrich quantitative studies.²² Understanding the impact of an HIV cure is fundamentally about the meaning of HIV in people’s lives and what might happen when an individual no longer has HIV. Few qualitative studies conducted in China are available in the English literature. We undertook this qualitative research to characterize social implications of curing HIV in HIV-infected PWID in Guangzhou, China, and to gain insight into the social context of HIV cure clinical studies.

Materials and Methods

Site

We selected Guangzhou, China, for our study due to the location of a well-established HIV treatment clinic, the Guangzhou Eighth People’s Hospital, and a centralized methadone maintenance treatment system. Our study site was uniquely positioned to examine the risk environment of HIV-infected PWID. Field observation took place for one month prior to interviews.

Subject recruitment

A purposive sample of HIV-infected PWID was recruited from the Guangzhou Eighth People’s Hospital and two district-based methadone clinics from October 2013 to March 2014. Physicians and social workers were interviewed to provide additional perspective and corroborate patient perceptions. Verbal consent was obtained from all participants. All participants received a phone card worth 100 RMB (approximately 16 USD) for their participation. All participants were told that there were no ongoing HIV cure trials in China and were encouraged to adhere to recommended ART regimens.

Interviews

A semistructured, in-depth interview guide (Supplement 1) was field tested among eight patients, two inpatient phy-

sicians, and three community leaders. Trained interviewers fluent in the local language (Cantonese or Mandarin) conducted interviews in a private location. The interview duration was 30 to 120 minutes. Interviews were audio recorded if consent was given; if not, field notes were taken. The interview topic guide elicited patients’ narratives on their medical care, personal relationships, injection drug use including methadone treatment, as well as their expectations and perceptions of a potential HIV cure. Given the rapidly evolving field of HIV cure research, we did not attempt to describe specific cure modalities but asked generally about the theoretical impact of an HIV cure on patients’ lives. We defined “cure” in the following ways: as an intervention (“the cure”), a state of being (“being cured”), and modifying perceptions of HIV (“if HIV became curable”). Care was taken to ensure that patients understood that there was no HIV cure yet and that they should continue to adhere to current medical recommendations. Emergent themes were explored further in subsequent interviews until thematic saturation was reached.

Analysis

Our methodological approach was based in grounded theory.²³ Interview transcripts were the sources of primary data. Transcripts were translated from Chinese to English and then analyzed using Atlas.ti software (Version 7, Atlas.ti Scientific Software Development GmbH, Berlin, Germany). Transcripts were coded independently and coding discrepancies were discussed to achieve consistency and reliability of interpretation (Supplement 2).

The UNC Chapel Hill Institutional Review Board (IRB) and Guangzhou Eighth People’s Hospital IRB approved this study. IRB approval from UCSF was deferred to UNC Chapel Hill.

Results

Interview data were analyzed from 29 patients, eight physicians, and three social workers (Table 1). The social effects of HIV infection and perception of HIV cure are presented in the context of three key relationships: patient–society, patient–health system, and patient–physician (Table 2).

Patients’ relationships with society

Effects of HIV. HIV infection resulted in isolation, decreased self-worth, and decreased social status. Patients felt inferior or “spoiled” for being HIV infected. As a result, patients disassociated with HIV-negative friends, and social networks narrowed. Patients traveled long distances away from their hometowns to work and seek medical care out of fear of disclosure.

“Right now it is like I have drawn a circle around myself.”
– Patient, 50 M

“I have become used to living alone for the past twenty, thirty years...I think I am a little inferior, that’s my feeling.”
– Patient, 47 M

Patients established new peer groups based on an HIV or PWID identity. Over time, some patients found new peer groups among other HIV-infected patients or PWID. Settings for peer support included methadone clinics (often facilitated

TABLE 1. HIV-INFECTED PEOPLE WHO INJECT DRUGS IN GUANGZHOU, CHINA: SOCIODEMOGRAPHIC CHARACTERISTICS

Age (years)	27–53
Gender	28 male, 1 female
Currently in methadone treatment	12 (41%)
Guangzhou urban resident ^a	17 (59%)
Highest education level completed	Elementary: 9 (31%) Middle: 13 (45%) High school: 6 (21%) College: 1 (3%)
Lowest CD4 count (self-report), average (cells/ μ l)	126
Unemployment	13 (45%)
Average income (USD/year)	3,150
History of detention ^b	76%
Average travel time to HIV clinic (minutes)	110
Number of hospitalizations for opportunistic infections	0: 9 (31%) 1: 15 (52%) 2: 2 (7%) 3: 3 (10%)

^aChina requires a household registration system (*hukou*) to maintain an accurate census and differentiate between urban and rural status.

^bPeople who inject drugs (PWID) are routinely arrested and detained at compulsory detoxification centers for months to years.

by social workers), the HIV outpatient clinic, church-sponsored drug rehabilitation groups, or online forums. Peer relationships were important for disseminating information about treatment and news of cure.

A patient described how a former injection drug user, whom he met in a drug detention center, has become a crucial source of social support:

“My friend has always been an elder brother I admire. When I feel reluctant to move forward, he would come to help me.” – Patient, 41 M

Finding peers allowed the patient to find mutual respect, understanding, and a sense of normalcy.

“In my circle, there is no such thing as shame. We are similar to each other and lead our lives like normal people.” – Patient, 51 M

Peer relationships helped patients establish a new sense of belonging in the face of feelings of inferiority.

“We tend to make friends with those who are also AIDS patients. I am a drug addict, so were all my friends...To be honest, I think I am an ‘inferior’ in society, so are my friends. We are low level people.” – Patient, 50 M

Other factors associated with perceived low social status included unemployment, low education background, and poor physical health. These factors contributed to a pervasive sense of fatalism within this peer group.

“All I hope for is that the people around me don’t look down upon me, so that I will hold an accepting attitude towards my death.” – Patient, 40 M

PWID relied on family for HIV care and protection against stigma. Families provided emotional and mental support for patients to ensure regular follow-up care, substance abuse recovery, medication adherence, and healthy habits. In many cases, immediate family members (parents and siblings) were the only people to whom the patients disclosed their HIV status. The family was seen as the locus of responsibility rather than the individual. Parents were sources of financial support during hospitalizations and outside of the hospital. Parental support was also protective against social stigma and maintaining social unity.

“If not even your family will support you, your life is meaningless, outside people will discriminate against you even more” – Patient, 39 M

TABLE 2. MEANING OF HIV INFECTION AND PERCEPTION OF AN HIV CURE

	<i>Meaning of HIV infection</i>	<i>Perception of HIV cure</i>
Patient–society	PWID view themselves as inferiors or social outcasts. Family and peer groups are protective against stigma and central to HIV care including medication adherence and emotional well-being. New peer support groups are established based on HIV or drug use, forming a new collective identity.	The possibility of being cured of HIV inspires hope among PWID with the possibility of reintegration into society. The curability of HIV would decrease fatalistic attitudes toward the disease and may reduce fear and stigma. Curing HIV may not change a patient’s identity as a formerly HIV-infected individual.
Patient–health system	HIV is an important national health priority with free comprehensive care and treatment for those who seek it. Many HIV-infected PWID remain outside of care due to stigma and other barriers. Methadone is an important point of entry to care for PWID.	Increased testing uptake and linkage to care may be a positive unintended consequence of cure research. PWID believe they will not have access to a cure even if it were available due to financial and other structural barriers.
Patient–physician	HIV specialist physicians establish relationships with their patients in a primary care-like model. Long-term physician–patient relationships increase trust and adherence. However, HIV-associated stigma is prevalent.	HIV cure may be a less desirable intervention when compared to ART, which is free, low risk, and highly effective.

Perception of HIV cure. Curing HIV may motivate patients to reenter society. Some patients felt that a cure for HIV would help them regain normalcy. The thought of being cured increased their hope for marriage, having children, finding employment, and regaining social mobility.

“Right now, I can’t even imagine having my own child. If I could be cured, I can think about having a baby. Otherwise, if I die, who will take care of my kid? So if I could be cured, everything would be different.” – Patient, 42 M

Curing HIV may not alter perceptions of the disease. Even if HIV were curable, social judgment directed against the behaviors associated with HIV transmission would remain.

“Even if this disease will be curable, getting this disease will never become a good thing.” – Patient, 42 M

“If you said I would see cured patients as normal people, I think that is very unlikely, I would always feel a little caution.” – Patient, 39 M

Curing HIV was related to syphilis, which is curable with penicillin but continues to engender prejudice as a sexually transmitted infection. Whereas social workers were likely to state that curing HIV could increase hope and self-efficacy, physicians were more likely to view an HIV cure in the context of other infectious diseases that have cures, but remain prevalent and stigmatized.

“It is like if someone has syphilis, would you act as if nothing happened? Syphilis can be cured.” – Physician, 41 M

Patients felt that curing HIV would not be enough to dissociate them from their HIV-positive identity and anticipated difficulty convincing others that they were cured.

“If people discriminate against you, it is the same if you are cured or not cured, because you had the disease before, right? For example, you had the disease, you tell someone that your disease is cured. Will the other people believe it? It is the same to me, to be cured or not. This thing is invisible.” – Patient, 37 M

Patients’ interactions with health systems

Effects of HIV. HIV strengthened the healthcare infrastructure. Patients were aware that they were eligible for free, first-line ART, free methadone, and access to HIV-specific subsidies and supplemental insurance. Methadone was an important point of entry to care for PWID, where HIV testing took place, and social workers facilitated referral to HIV specialists and other resources. Despite these policies, patients and social workers also felt strongly that most HIV-infected PWID remain outside of care due to stigma, fear of disclosure, and ancillary costs of care including transportation and diagnostic tests.

Perception of HIV cure. An HIV cure would increase hope and linkage to care. Patients, physicians, and social workers believed that a cure would motivate currently untreated HIV-positive PWID to be tested sooner and seek care, before the development of symptomatic opportunistic illnesses requiring hospitalization (78% of our subjects were hospitalized at least once for an AIDS-defining condition). The perception of HIV as a curable disease could inherently alter fatalistic attitudes toward the disease.

“If HIV could be cured, there would be great hope for life. [PWID] will have more motivation to get treated or tested, or even motivate others to get tested and treated. Many patients

refuse treatment because of their assumptions about HIV. They think that HIV is incurable, and treatment is ineffective. So they would rather maintain their quality of life and indulge in drugs. In other words, if HIV could be cured, they would adopt a more positive attitude and alter their behaviors.” – Social worker, 27 M

Some PWID avoided HIV testing and treatment for other reasons, including fear of disclosure and stigma and becoming labeled as HIV positive. A fundamental shift of HIV from incurable to curable could normalize the disease, increasing hope and motivation for patients to address both HIV and substance abuse issues.

“If it can be cured...it is the same as getting a cold. You can cure it completely, so there is no discrimination anymore. The main problem is that it is incurable.” – Patient, 39 M

In contrast, the greatest perceived barrier was financial, and hopefulness toward a cure was tempered by personal poverty.

“If you have money, you can have hope. People like me don’t...new medicines that come to China will always cost us money. I won’t be able to afford it, so I don’t have much hope.” – Patient, 40 M

Behavioral disinhibition with an HIV cure is uncertain. On the one hand, patients did not believe that drug use would become a less harmful practice even if HIV were curable, citing financial and social consequences as primary deterrents. There was little awareness of drug use as a high-risk behavior for HIV transmission.

“Drug use is drug use, while HIV is HIV, they are not equal. Not every drug user has HIV.” – Patient, 38 M

On the other hand, physicians expected to see some increase in risk behaviors if HIV could be cured, drawing parallels with the increasing incidence of sexually transmitted infections despite the availability of effective antibiotics.

Patients’ relationships with physicians

Effects of HIV. HIV specialist physicians established primary care relationships with patients. Management of HIV as a chronic disease facilitated continuity of care, with regular follow-up. This facilitated long-term patient relationships in the setting of perceived widespread stigma within the medical community. As a result, the HIV specialist functionally became a primary provider and managed other medical conditions. Physicians were also gatekeepers to specialists and social services for HIV-infected PWID.

Long-term physician–patient relationships increased trust. Across clinic settings, physicians were seen as a source of authority and expertise. Patients reciprocated with respect, acceptance of medical recommendations, and high levels of trust.

“I don’t know if treatment will work, but if the doctor told me I should be treated, I will obey. My thought is, I’m not sure of the medical outcome, but I have faith in my doctors’ opinions.” – Patient, 39 M

Physicians also believed that providing hope for patients was important in maintaining a therapeutic relationship. This “healer’s relationship” promoted medication adherence, abstinence from substance abuse, attendance at follow-up visits, and a positive outlook about HIV. It was a means of communicating trusted information and managing expectations for HIV.

HIV-associated stigma by medical professionals was prevalent. Many patients experienced refusal of care by medical providers due to their HIV status. This delayed initiation of ART and other necessary interventions.

“When the doctors found out I had HIV, they refused my surgery...they said they would have to throw all their equipment away.” – Patient, 47M

Fear of infection and lack of understanding about HIV were the main contributors to stigma.

Perception of HIV cure. Early HIV cure research may be a less desirable intervention when compared to ART. Physicians believed that a cure might not be necessary for many of their patients because of the demonstrated success of free ART in controlling HIV. Some physicians had already described ART in terms of “cure” (*zhihao*) as motivation for medication adherence to achieve undetectable viral loads. Physicians were concerned that HIV cure research should not overshadow the importance of increasing access to ART regimens. They were also concerned that a cure available only to a select group of patients may undermine trusting, established relationships with patients.

Discussion

Understanding the social effects of an HIV cure will require us to combine the science of treating disease with the art of healing illness, the latter of which requires careful attention to psychosocial aspects of care and awareness of the social conditions of HIV infection.²⁴ In this focused study of HIV-positive PWID in Guangzhou, China, we describe an HIV illness narrative and investigate perceptions of an HIV cure among this key affected population. Our results in each of three key domains (patient–society, patient–health systems, and patient–physician) provide insight into the design and implementation of HIV cure clinical trials (Table 3).

This study is part of a larger multiinstitutional, multidisciplinary research effort to investigate the biosocial implications of curing HIV infection in order to develop a theoretical framework about HIV cure research and early implementation, to determine HIV cure stakeholder perspectives, and to develop an online forum to promote stakeholder engagement.⁵ Our empirical data represent a biosocial approach to understanding HIV and will inform future research questions for formal stakeholder analysis and community engagement.

Community support from family, friends, and peer groups was an important coping mechanism for patients living with HIV. This is consistent with the existing literature on the positive impact of social support for HIV-infected individuals.^{25–27} Other studies in both Western and non-Western contexts have shown that social support is protective against stigma, can increase physical and mental resilience, and can improve medication adherence and other health-related behaviors.^{28,29} This supports the need to provide comprehensive psychosocial support for patients and to engage families and peer networks in HIV cure research trials.

Hope was a dominant theme that emerged in our discussions of HIV cure, particularly in healthcare settings. Health workers (physicians and nurses) were some of the most important “others” in patients’ lives and were seen as key sources of support, strength, and hope in the face of persistent stigma. Hope has been described as important for resilience, community building, and overall health outcomes.¹ However, hope may also lead to the dangers of therapeutic misconception, a failure to distinguish between research and clinical treatment.³⁰ Failure to manage expectations in early preexposure prophylaxis studies led to mistrust and premature termination of clinical trials.³¹ Supporting the formation of honest and mutually accountable relationships among patients, physicians, social workers, and other medical professionals may mitigate some of the risks of HIV cure research.

TABLE 3. IMPLICATIONS FOR HIV CURE RESEARCH TRIALS

<i>Implications for HIV cure research trials</i>	
Patient–society	<p>Hope is a salient new theme in HIV cure research. Patient expectations should be accurately assessed, particularly when the goal of research is common scientific knowledge with minimal chance of individual benefit.</p> <p>HIV research trials should identify, empower, and include key populations affected by HIV who have not traditionally been enrolled in HIV research studies, such as PWID.</p> <p>Increasing capacity for psychosocial services, particularly in middle–income countries, is critical in all stages of cure research and will strengthen existing systems.</p>
Patient–health system	<p>Local HIV testing, treatment, and harm reduction capacity should be scaled up in anticipation of increasing numbers of HIV-positive patients seeking care.</p> <p>Supporting methadone clinics and expanding harm reduction services may facilitate engagement in care of PWID and enrollment in cure trials.</p> <p>Discussion of posttrial access to cure and financial costs for key affected populations should begin early and engage international stakeholders.</p>
Patient–physician	<p>HIV-associated stigma within the medical profession should be systematically addressed in settings where it is prevalent, with emphasis on maintaining confidentiality to preserve physician–patient trust.</p> <p>HIV specialists are important patient advocates and decision makers, particularly in local settings without primary care-based health systems, and should be considered key stakeholders in cure research and trial design.</p>

Our finding that an HIV cure may motivate testing and linkage to care among PWID has important public health implications. This finding is consistent with improvements in testing rates that occurred after the development of other cures for sexually transmitted diseases, such as penicillin and salvarsan for syphilis.³² Qualitative research has suggested that the incurability of HIV contributes to fatalism and low HIV test uptake.^{33,34} However, HIV cure research may reframe the disease as potentially curable, promoting early testing and linkage to care that could be synergistic with ongoing treatment as prevention programs.³⁵

HIV cure clinical research designs should consider both post-trial access and conducting research among under-represented, key affected populations such as PWID. Financial concerns were already emerging as a barrier in a health system in which patients are dependent on government policies for free medication. An HIV cure was perceived as a high-tech intervention that would be largely inaccessible to low- and middle-income countries for a long time. This perception implicates the history of access to antiretroviral therapy both in China and other middle- and low-income countries, which occurred in delayed, yet incremental advances.¹⁷ Unless existing health disparities are systematically addressed, a cure may represent yet another unattainable health intervention beyond patients' reach and highlight existing social and structural barriers affecting PWID.

Conclusions

This qualitative study characterizes the social meaning of HIV among PWID, a key affected population, in Guangzhou, China, and investigates perceptions of an HIV cure in preparation for cure clinical trials. By understanding the meaning of HIV and the implications of a cure, we identify possible opportunities and challenges for HIV clinical trial research from the perspective of social and health systems. The possibility of curing HIV may bring hope, increase linkage to care, and increase self-efficacy for PWID. However, existing social and structural factors that define an individual's risk environment cannot be addressed by a biomedical cure alone. Conducting cure research fundamentally shifts our approach to HIV research by altering the perceptions and expectations of key affected populations and other stakeholders. Considering the social aspects of cure research is an important step in creating synergy with existing HIV treatment and prevention programs. The long-term success and global impact of HIV cure clinical trials will require understanding of diverse social contexts.

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Author Disclosure Statement

P.V. is on the scientific advisory boards for Gilead and Bristol Myers Squibb and on the Data and Safety Monitoring Board for Merck.

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