

HIV self-testing among men who have sex with men in China: a qualitative implementation research study

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Abstract

Background: HIV self-testing (HIVST) may expand HIV testing, but there have been few pilot programmes among men who have sex with men (MSM). This purpose of this study was to evaluate HIVST implementation among MSM in China using qualitative methods.

Methods: We undertook semistructured interviews among MSM and those organising HIVST programmes for MSM. Purposive sampling method was used to ensure men with different HIV serostatuses, ages and HIVST frequencies were included. Men were recruited from MSM community-based organisations and a local HIV clinic. An implementation science framework was used to interpret the findings. Two individuals used a standard code-based methodology to identify themes.

Results: Forty-two MSM and six stakeholders were interviewed. Our data showed many MSM and stakeholders preferred HIVST to facility-based testing. Most men reported that HIVST empowered MSM and informed sexual decision making. Many men noted that decreasing the HIVST price may increase demand. Some men noted that HIVST could be scaled up through social media and by modifying bulky packaging. Minimal adverse events were reported.

Conclusions: HIVST may expand HIV testing and promote empowerment of MSM. Minimal adverse outcomes were noted, but further implementation research is needed.

Key words: HIV, self-testing, implementation, MSM, China

Introduction

HIV self-testing (HIVST) has rapidly expanded in many settings. HIVST is defined as a process whereby a person who wants to know his or her HIV status collects a specimen, performs a test and interprets the test result in private [1]. Countries around the world have varied widely in the degree to which they have adopted and implemented self-testing [2]. The unsupervised nature of HIVST makes it difficult to study in research settings, and these knowledge gaps have contributed to concern about adverse outcomes, including severe psychological distress or suicide, intimate partner violence, coercion and poor follow-up [3]. HIVST pilot studies in Malawi [4], Kenya [5], Singapore [6], China [7], Canada [8] and the USA [9–11] have suggested the acceptability and feasibility in structured settings. However, there is less literature on HIVST in implementation contexts. HIVST may be different in implementation contexts compared with research contexts because of less supervision, fewer resources available during and after testing, and less stringent quality controls.

In China, HIVST kits are easily available through e-commerce websites [12] as well as government-sponsored pilot initiatives [13]. There are no specific national policies or guidelines

regulating the sale of test kits, but there is already widespread use among men who have sex with men (MSM) [14]. Similar to global trends [15,16], MSM in China bear a disproportionate HIV burden [17], and expanding HIV testing in this key population is an urgent priority [17]. Nationwide data show that almost a quarter of Chinese MSM report ever using an HIVST kit [14,18,19], and yet no centralised governing body regulates the distribution or use of these kits. Instead, HIVST kits are available to the public over the internet via private online vendors [12] or through pilot research interventions sponsored by partnerships between local community organisations and the government [20]. This provides an opportunity to examine the lived experiences of HIVST from the perspective of men testing themselves. The purpose of this study is to use qualitative methods to better understand HIVST among MSM in order to inform public health programmes and research.

Materials and methods

Study setting and participant eligibility

This study was conducted in the city of Guangzhou, a densely populated metropolitan area on the southern coast of China with a large migrant population [21,22]. Research protocols were approved by institutional review boards from the Guangdong Provincial Dermatology Hospital, Guangzhou Number Eight People's Hospital and the University of North Carolina. The research team collaborated with local infectious disease clinics and LGBTQ-centred community organisations to recruit participants onsite

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at community organisations or local clinics. A dedicated research assistant and study coordinator screened referred participants for the following inclusion criteria: age ≥ 18 years, self-reported male gender, self-reported intercourse with a male ever (anal, oral or unspecified) and self-reported use of an HIVST kit. Stakeholders were identified with the help of collaborators at partnering sites. Individuals who worked with the target population of MSM in any professional capacity (with or without direct service provision) were eligible, including authorities in the municipal public health department, MSM community workers and leaders, physicians specialising in MSM-specific health issues and HIV researchers.

Recruitment

One of the recruitment sites was GZTZ, a large MSM-focused community organisation that launched an HIVST programme in 2007 to supplement their existing HIV testing services [20]. The initiative received both funding and logistical support from the government, with the regional Centers for Disease Control (CDC) assisting in training personnel, purchasing supplies and quality control. Their online platform offered HIVST as part of a comprehensive package that provided educational information, usage instructions with clear illustrations, web-based customer support from CDC-trained personnel, fast direct shipping and a rebate programme to encourage reporting of results (which refunded a USD23 deposit). Those who uploaded positive results or did not upload results were actively followed up through programme outreach. Additionally, telephone support was available between the hours of 0900 and 2200.

Semi-structured interviews

MSM participants were purposively sampled between February and June 2016 to ensure a diversity of HIV serostatuses, ages and HIVST frequencies. Semi-structured interviews were conducted in person in private counselling rooms at the GZTZ clinic or Number Eight People's Hospital, unless the participants lived in a different city and telephone interviews were used. Interviews lasted between 30 and 40 minutes. Interview questions were structured in several major domains: (1) decision-making process when choosing to HIV self-test; (2) actual experiences with HIVST; (3) perceived advantages and disadvantages of HIVST based on personal experience; and (4) background information regarding sexual orientation, social and familial relationships, socioeconomic status and level of disclosure regarding sexual orientation (Supplemental Data 1, Interview Guide). Individuals were provided the equivalent of USD15 for participating. In-depth interviews with stakeholders were conducted between July and August 2016. Interview questions for stakeholders were structured in these major domains: (1) basic background information regarding their professional position; (2) level of knowledge regarding HIVST and (3) actual experience with HIVST, whether through policy work, organising HIVST programmes, interacting with clients/individuals, research or other mediums, particularly if any experiences involved obtaining governmental support. All interviews were conducted in Mandarin Chinese by two research assistants with formal training in qualitative methods.

Data analysis

Interviews were recorded, transcribed and checked for accuracy. Two independent individuals read all of the data in order to identify preliminary themes for the code book. The code book was generated using both deductive and inductive methods. Two individuals constructed and checked the codebook. Transcripts were imported into Nvivo QSR (QSR International, Doncaster, Australia) software for data analysis.

We used implementation science as a framework [23] to structure the data analysis. The general HIVST implementation science evaluation framework contains the following stages [23]: identifying gaps in existing HTC service provision, developing new HIVST interventions, implementing and disseminating interventions, measuring effectiveness and efficiency, and reviewing data to inform improved service provision.

Results

Background characteristics

In total, 42 MSM and 6 stakeholders were interviewed. As shown in Table 1, the mean age of MSM was 26 years (range 21–35 years). Seven men were students and 35 were employed. Approximately 88% had a college education or less, and most participants (66.6%) had an annual income greater than USD10,000. Eighty-eight percent of men identified as gay, while 9.5% identified as bisexual. Most men (83%) had facility-based HIV test experience. Seven men used HIVST as their first-ever HIV test. Nine men used HIVST three or more times. Four men were living with HIV

Table 1. Demographic characteristics of men who have sex with men in China, 2016 ($n=42$)

Variables	Mean (range)	SD
Age	26 years (21–35)	3.72
	<i>n</i>	%
Occupation		
Students	7	16.7
Non-students	35	83.3
Education		
High school/vocational school	16	38.1
Current college students/college	21	50.0
Graduate school	5	11.9
Self-reported disclosure of sexual identity		
Out to family, friends and/or doctors	3	7.1
Not out to family, friends and/or doctors	39	92.9
Annual income (USD)		
Under 10,000	14	33.3
10,000–16,667	16	38.1
>16,667	12	28.6
Sex orientation		
Gay	37	88.1
Bisexual	4	9.5
Not sure	1	2.4
Facility-based test experience		
Yes	35	83.3
No	7	16.7
Frequency of HIV self-testing		
1–3 times	33	78.6
More than 3 times	9	21.4
HIV status		
Negative	38	90.5
Positive	4	9.5

and the 38 did not have HIV. Among stakeholders, we interviewed two leaders from LGBT community groups, two government employees at the municipal health department (Guangdong CDC), one sexual health physician who specialises in working with the Chinese MSM population and one public health researcher that studies HIV testing in China.

We identified a total of six themes: preference for HIVST to facility-based testing; HIVST was associated with minimal adverse outcomes; HIVST encouraged safer sexual decision making and more frequent testing; MSM community organisations facilitated HIVST uptake; social media increased HIVST awareness; and high cost and bulky packaging discouraged HIVST.

Many MSM and stakeholders preferred HIVST to facility-based testing. Twenty-six of 42 MSM and 4/6 stakeholders preferred HIVST to facility-based testing. Those who preferred HIVST frequently noted that convenience and confidentiality were important factors compared to facility testing. For the large proportion of MSM in our study who were not open about their sexual orientation, HIVST was a more accessible testing option. Sixteen men mentioned that purchasing kits online reduced their risk of undesired or accidental disclosure. Eight men observed that HIVST offered a chance to avoid the embarrassment of talking to doctors about their sexual behaviours, and several men felt that they would rather receive positive results in the comfort of their own home. Thirty-five men who used HIVST kits reported a greater sense of agency due to more control over the time, place and context of testing (e.g. who was present during testing). Most participants advocated for continued use of HIVST as a screening tool rather than as a replacement for hospital- or facility-based HIV testing services. As such, while most participants did indeed prefer HIVST to traditional facility-based HIV testing, they expressed support for GZTZ's clinic-based HIV services, stating that the optimal situation is to use HIVST as a supplement to facility-based HIV services.

HIVST was associated with uncommon adverse outcomes, similar to facility-based testing. Thirty-five men had both facility-based testing and HIVST experiences. First-time HIVST experiences were associated with transient anxiety and distress related to using the kit, but these uniformly diminished with repeated self-testing. At the same time, the four men in the study who received a positive HIVST result reported feelings of depression, hopelessness and suicidal thoughts. All four men called a hotline for further support and followed up with confirmatory testing that led to subsequent HIV treatment. No men reported adverse outcomes such as coercion or violence. Stakeholders that participated in the organisation of the GZTZ online HIVST platform reported no episodes of self-testers reporting suicidality, coercion or violence.

HIVST encouraged more frequent testing and informed sexual decision making. In our study, six participants said that they tested more due to the convenience of HIVST technology, and any single instance of usage reinforced their willingness to test again. Some expressed that without this technology, they would have further delayed seeking testing. No participants reported experiences with HIVST at the point of sex, or being asked to HIV self-test just prior to a sexual encounter. However, many expressed interest in proposing HIVST to a casual partner at the point of sex. Two participants relayed that friends had used HIVST at the point of sex and then used the results to make decisions about condom use or having sex at all. When asked how the results would guide sexual decision making in hypothetical scenarios, many men responded that a negative HIVST result bring 'peace of mind' but did not concede that they would be more

likely to omit condoms. In fact, most men reported that HIVST brought about an increased general awareness of HIV, and this exposure to the concrete risks of condomless sex encouraged more precautionary measures.

MSM community organisations facilitated HIVST uptake. Given that the HIVST programme was embedded in an MSM community-based organisation, men trusted the programme. Twelve men said that community groups like GZTZ were trustworthy and have a long history of organising gay rights advocacy, in addition to providing comprehensive HIV testing services at the local level. Second, stakeholders mentioned that GZTZ has a strong partnership with the local CDC, which provides high-quality testing kits and ensures strong testing systems.

Social media increased awareness of HIVST and provided an online platform to order test kits. Many MSM in Guangdong knew about self-testing through GZTZ's social media account. The HIVST program used WeChat, a hybrid between Facebook and Twitter, to publish posts about sexual health. Men could also order test kits through this site and have them delivered through the post. One stakeholder mentioned that online advertising can effectively reach young MSM subgroups that spend more time online. This stakeholder also mentioned HIVST can better reach hidden MSM who do not access facility-based services. Public online praise of the online HIVST platform established mutual trust.

Some MSM noted that high cost and bulky packaging discouraged HIVST. Four MSM said that cost is a primary barrier for HIVST. They stated that USD8 per HIV/syphilis blood rapid test kit package would be a more reasonable cost for the tester, as opposed to the USD23 price charged by the non-governmental organisation or the USD19–USD46 prices from online vendors. With regard to kit presentation, participants disliked anything that was non-discreet, such as bulky packaging and salient logos that could be associated with HIV or gay life. Many feared that this would lead to stigma and exposure of sexual orientation.

Discussion

We found that HIVST is highly acceptable, preferred to facility-based HIV testing and has necessary infrastructure in place to support scale-up in this single location. This study expands the literature by focusing on HIVST among MSM, using an implementation science framework and including only individuals with personal experience undergoing or organising self-testing. To our knowledge, this is a rare instance of stakeholder perspectives on organising routine HIVST programmes outside of a structured research study.

Our study found minimal adverse outcomes reported among MSM who used HIVST. A number of concerns have been raised with HIVST, including psychological distress, suicidality, depression, physical violence and social harm [17–19]. Though we found individuals reporting some anxiety with testing and extreme emotions with positive results, these emotions were found to also be present if occurring in a facility-based context and diminished with repeated testing, as well as the availability of counselling. In our study, no instances of HIVST-associated partner testing, testing at the point of sex or coercion were observed. Men receiving positive HIVST results benefited from local community resources, such as community-based organisations and online support forums, which guided all of them to seek confirmatory testing and further care.

Our study suggested that social media may facilitate HIVST scale-up. This is consistent with research in China and the USA [24]. In our study, most HIVST users heard about HIVST from social

media. The detailed instructions within a trusted MSM platform helped men to learn about and benefit from HIVST. This is consistent with a US study which also found that gay social networking applications could promote HIVST [25].

Our study has several limitations. First, most MSM had purchased HIVST kits through the GZTZ pilot programme rather than through regular e-commerce websites, thus compromising the generalisability of our findings to MSM in other cities. We were able to interview only two men who used HIVST without this platform. However, there are many HIVST platforms in other Chinese cities that are collaborations between the Chinese government and local community groups [26]. Additionally, we were not able to interview any MSM who may have heard of but never used HIVST, who may provide additional insight on barriers to HIVST. Finally, we interviewed only four men living with HIV, impacting our ability to evaluate linkage to care and downstream effects on the HIV care continuum.

Despite the high acceptance of HIVST among MSM in China, official HIVST guidelines remain in flux. National HIV testing guidelines have yet to include HIVST, and online sales are neither banned nor officially permitted. Yet in this grey area, many HIVST services have emerged in China. The results of this study indicate that the MSM community constitutes a considerable market for HIVST, but implementation needs to incorporate a comprehensive service package, including counselling and linkage services. Government cooperation with local community groups plays a critical role in the success of these ventures and illustrates the importance of government–community partnerships. The government provides resources and technical support, while the MSM community organisation provides access to men and trust. The model established by GZTZ could be rolled out to other major cities in China in order to further assess implementation. More quality assessment and research on linkage to care are needed.

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Conflicts of interest

The authors declare no conflicts of interest.

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Supplemental data 1: interview guide

Part 1: social and demographic information

- 1) Gender, age, occupation, highest level of education completed, income
- 2) How long they have been in current place of residence
- 3) Sexual identity, marriage status (*PROBE: out to anyone? Family, friends, doctors*)

Part 2: warm-up, knowledge and attitudes for HIVST

- 1) Where have you used facility-based HIV testing service? (*PROBE: CDC, community-based organisations [CBO] or hospital*)
 - a) How often?
 - b) Ever been positive? When? Where?
- 2) Can you tell us what you know about HIV self-testing (HIVST)?
 - a) How did you learn about it? (*PROBE: who/where? Online, friend, professional, CBO, CDC*)
 - b) How do you feel about HIVST? What is the meaning of HIVST to you? (*PROBE: test of triage or screening test?*)
 - c) Did you prefer it to other forms of testing? Why?
 - d) How often do you use HIVST?
- 3) *For refusers of HIVST: Why did you choose not to use HIVST? (PROBE: concerns)*

Part 3: personal experiences with HIVST

- 1) Can you recall and describe in detail your *first time* using an HIVST kit? (*If the first time was too long ago and they don't remember well, then substitute Q4*)
 - a) How did you obtain it? (*PROBE: GZTZ online, CDC, friend, e-commerce websites*)
 - b) What type of HIVST kit did you use, oral or blood?
 - c) Was this your first time testing for HIV?

If yes: What barriers to facility-based testing did HIVST overcome?

If yes: Did using an HIVST encourage you to later get facility-based testing?

If no: Did HIVST help to increase your HIV testing frequency?

- d) Context (*PROBE: Anyone force you?*), why (*PROBE: motivators*), when, where
 - e) What was your initial reaction to the result? (*PROBE: anxiety/depression/suicidality*)
 - f) How did you feel about the accuracy of your result? Do you trust it?
 - g) How did you feel about the process? Any difficulties?
 - h) Did you tell any one of your result? (*PROBE: partners, GZTZ*)
 - i) Did you receive any money for returning your result? (*PROBE: community engagement*)
- 2) What motivated you to choose HIVST? (*PROBE: facilitators vs barriers*)
 - a) Facilitators? (*PROBE: convenience, privacy, empowerment/agency/autonomy*)
 - b) Barriers? (*PROBE: cost, reliability/quality*)
 - 3) Concerns before/during/after? (*PROBE: stigma, confidentiality/ protection of privacy*)
 - 4) Can you talk about your most recent HIVST experience? (*repeat Q1a–g*)
 - 5) Have you ever bought an HIVST kit from any ecommerce websites (Taobao)?
 - 6) In what ways have your HIVST experiences affected your life? (*PROBE: increase test frequency, condom usage*)

Part 4: sexual relationships (HIV –/+)

- 1) Did you tell anyone about your result?
 - a) Did you tell your primary partner?
 - b) Did you experience any intimate partner violence? (*PROBE: physical/emotional/financial*)
 - c) Did he/she get tested soon afterward? What is his/her result?
 - d) How did you feel about it? How does it affect your relationship with him/her?

- 2) Have you ever used HIVST at the point of sex?

If yes: Was it an oral or blood sample HIVST kit?

- a) If so how often?
 - b) With casual and/or regular partner(s)?
 - c) Did you ask someone to take it or did someone ask you to take it? (*PROBE: coercion*)
- 3) Has a partner ever suggested you to use HIVST before sex? (*PROBE: Did anyone force you?*)

If yes: Was it an oral or blood sample HIVST kit?

Part 5: post-test linkage to care and adverse outcomes

- 1) Did you confirm your results at a hospital or CDC? (*PROBE: facilitators/barriers to confirmation*)
 - a) Did you get post-test counselling or other support services?
 - b) Did you get your CD4 results? Where? What was the process? Did you go to see a doctor?
 - c) Did you inform GZTZ of the result? (*PROBE: community leadership in HIV prevention*)
 - d) Have you been to any self-help groups? CBO?
 - e) Did you talk to your friends about this? Did they offer you help/advice? How do you feel about it? Anything changed?
- 2.1) *For positive HIVST:* Some people who have used HIVST have experienced (a–c). Did you?
 - a) Depression, hopelessness, suicidal feelings
 - b) Coercion or being forced by others to take it
 - c) Violence or abuse from intimate partners? (*PROBE: physical, financial, emotional*)
- 2.2) *For both negative and positive HIVST:* Some people who have used HIVST have experienced more convenience and/or a greater sense of control over their lives. Did you? (*PROBE: empowerment, agency, self-efficacy*)

Part 6: conclusion

- 1) Is there anything else you would like to add about your experiences with HIVST?
- 2) Do you have any questions or suggestions?