

A Rocky Road to Resiliency: An Exploration of GetaKit by BlackCAP

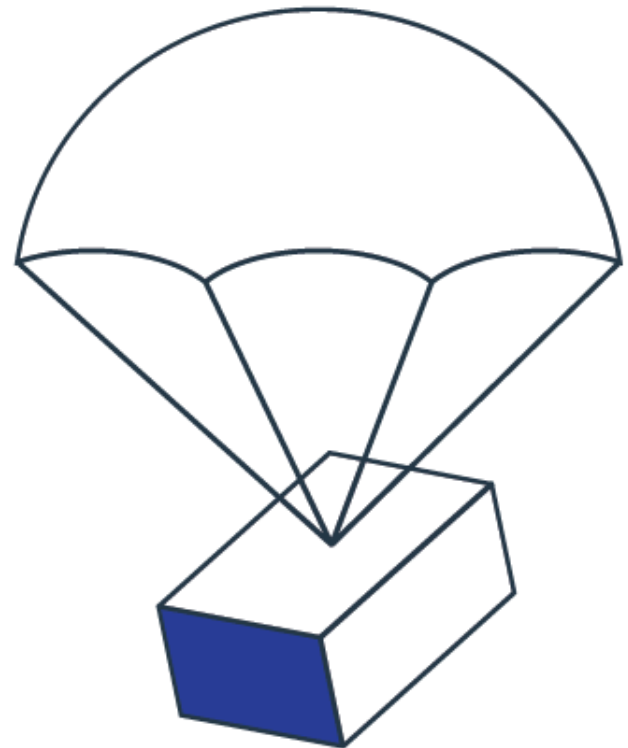
Qualitative

To explore the reasons for choosing the HIV self-test and the low report rate among ACB gbMSM qualitative data was collected through a focus group. Findings showed that ACB gbMSM have complex, and at times conflicting, views regarding their use of HIV testing and reporting.

Participants of the focus groups shared that they preferred the HIV self-test because of its ease and convenience. Some participants described HIV and a “community infection” that should be managed by “community”. This may involve one person having multiple HIV self-test kits to share with others who prefer to not engage directly with the healthcare system.

Results reporting to GetaKit remains under 50% among gbMSM from ACB communities. When this was discussed in the focus group, participants shared that they wished to maintain their privacy and confidentiality, preferring to speak directly to Black-CAP – an AIDS Service Organization in Toronto that serves ACB clients.

These findings suggest that preference for HIV self-testing can be viewed as evidence of community resiliency. However, it is still important to be cautious that widespread distrust of the healthcare system does not manifest as a maladaptive form of resiliency.

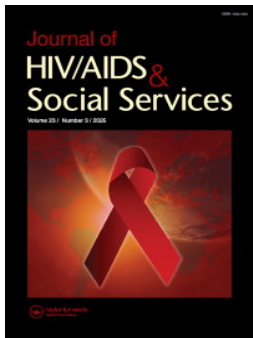


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A rocky road to resiliency: An exploration of GetaKit by BlackCAP

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ABSTRACT

In Ontario, HIV diagnoses continue to remain highest among individuals who identify as gay, bisexual, or men who have sex with men (GBM), as well as persons of African, Caribbean, or Black (ACB) ethnicities. To address this, GetaKit, an internet-based service allowing for individuals to acquire a free HIV self-test (HIVST) partnered with the Black Coalition for AIDS Prevention (BlackCAP), an AIDS service organization in Toronto. As part of a larger mixed methods study, this work builds upon the quantitative data already published to explain the testing behaviors of ACB GBM. Using a focus group, this study supports what is already known about culturally sensitive health interventions to support community resiliency and liberation. However, the findings also demonstrate that there exist issues which threaten to undermine the fecundity of HIVST as a resiliency building tool, including concerns around trust, privacy, and misaligned, at times apotropaic, beliefs around the test itself.

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Background

HIV disproportionately affects specific groups, two of which are gay, bisexual, and men who have sex with men (GBM), and persons of African, Caribbean, or Black (ACB) ethnicities. In Ontario, in 2022 (last year of published data), based on exposure category, GBM accounted for 56.8% of new HIV diagnoses, while accounting for only 4.1% of the Ontario population; meanwhile, based on ethnicity, ACB persons accounted for 29.8% of new HIV diagnoses, while accounting for less than 5% of the Ontario population (Ontario HIV Epidemiology and Surveillance Initiative (OHESI), 2023). When taken together, ACB GBM account for 33% of new

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HIV diagnoses in the GBM community; while diagnoses among White GBM have steadily decreased since 2018, diagnoses in racialized communities have either increased or remained stable, even if the raw number of diagnoses decreased, compared to White GBM. Notably, 49.1% of new HIV diagnoses among women were in ACB women (Ontario HIV Epidemiology and Surveillance Initiative (OHESI), 2023), signaling an unequal burden among this subgroup as well.

Importantly, testing is one strategy to address ongoing inequitable HIV transmission among ACB GBM populations. By identifying persons' HIV status, tailored risk reduction counseling can occur, including the benefits of HIV pre-exposure prophylaxis (PrEP) and of suppressed viral loads from HIV treatment. Research shows that, when an HIV-positive person takes antiretroviral therapy and achieves an undetectable viral load—that is, when the virus becomes undetectable in blood—HIV transmission no longer occurs (i.e., undetectable = untransmittable) (Eisinger et al., 2019). Likewise, when an HIV-negative person takes a low dose of antiretroviral medication before a potential HIV exposure (i.e. pre-exposure prophylaxis or PrEP), their risk of HIV acquisition is reduced by over 99% (Centers for Disease Control and Prevention (CDC), 2021a, 2021b; Tan et al., 2017). While these prevention outcomes are remarkable, both require that persons undergo HIV testing—making testing the key entry point into prevention and care.

In Canada, the newest strategy to help people know their HIV-status is HIV self-testing (HIVST), which international research suggests corresponds with increased testing frequencies, more uptake among first-time testers, and higher user satisfaction, compared to traditional testing approaches (Eshun-Wilson et al., 2021; Jamil et al., 2021; Ontario HIV Treatment Network, 2019; Witzel et al., 2020). Other research shows that members of ACB communities may prefer self-testing compared to serology, particularly if they have experienced stigmatization by healthcare providers or in healthcare settings (Hawk et al., 2020; Mathews et al., 2020).

The impacts of stigmatization and race on one's ability to access healthcare is also repeated in the research around ACB communities and resiliency (Holden & Jones, 2024; Reed & Miller, 2016). Generally, this body of work conceptualizes resiliency as an individual's ability to adapt to adverse circumstances (individual resiliency), as well as whether they can draw on personal support networks (community resiliency). Taking a strength-based approach, this research focuses on individual agency and self-efficacy in the face of social challenges, as well as the ways in which one interacts with the resources available to them in their community (Town et al., 2024). Within this work, a significant amount of literature has been penned that

specifically focuses on the relationship between HIV testing and resiliency for ACB GBM. Numerous studies have indicated a positive relationship between resiliency and the rate of HIV testing, as well as increased resiliency, specifically ACB community resiliency, being linked to a decrease in HIV risk behaviors (Antabe et al., 2023; Bogart et al., 2013; Earnshaw et al., 2013; Liu et al., 2025).

In response to HIV's disproportionate impact on ACB GBM and guided by the literature on the resounding success of HIVST's ability to reach the ACB GBM community, GetaKit, an online ordering platform for free HIVST, partnered with the Black Coalition for AIDS Prevention (BlackCAP), an AIDS Service Organization (ASO) in downtown, Toronto, that specifically serves the needs of the ACB community. While we have previously published on the pilot study, screening system, and preliminary results for GetaKit (O'Byrne et al., 2021a, 2021b, 2021c), as well as some of the quantitative ACB GBM data that was obtained shortly after GetaKit's launch, herein we report on the most recent ACB GBM data that was obtained, and on the qualitative investigation it led to. More directly, this study makes use of an explanatory mixed methods design, whereby the administrative data for ACB GBM was descriptively analyzed and the results used to develop focus group questions that sought to answer two questions: first, why do ACB GBM use a HIVST over other HIV testing methods? And, second, why do ACB GBM have such high rates of ordering HIVSTs via GetaKit, but such low rates of reporting their results? Through a mixed inductive-deductive thematic analysis of these men's complex interactions with HIV testing and their communities, this analysis seeks to uncover how HIVST can be conceptualized as a tool for increasing resiliency, albeit one that must be wielded carefully if its full potential is to be realized.

Study design & methods

The mixed-methods sequential explanatory design, popular among researchers in behavioral and social sciences (Caracelli & Greene, 1993; Colins, 2010; Creswell & Plano Clark, 2018; Janz et al., 1996 in Ivankova et al., 2006), involves collecting and analyzing first quantitative and then qualitative data in two consecutive phases within one study (Creswell & Plano Clark, 2007). The researcher first collects and analyzes the quantitative (numeric) data, then the qualitative (text) data are collected and analyzed to explain, or elaborate on, the quantitative results obtained in the first phase. The rationale for this approach is that the quantitative data and their subsequent analysis provide a general picture of a pattern of results that provide the basis of the research problem, and the qualitative data and

their analysis refine and explain those statistical results by exploring participants' views in more depth (Creswell et al., 2003 in Ivankova et al., 2006; Rossman & Wilson, 1985; Tashakkori & Teddlie, 2010). The rationale for mixing both kinds of data within one study is grounded in the fact that neither quantitative nor qualitative methods are sufficient, by themselves, to capture the meaning of certain patterns of results. When used in combination, quantitative and qualitative methods complement each other and allow for a more robust analysis, taking advantage of the strengths of each (Caracelli & Greene, 1997; Johnson et al., 2007; Miles & Huberman, 1994). All aspects of the study design, including the ways in which participants were recruited and data analyzed, was approved by the ethics committee of the University of Ottawa.

Quantitative methods

GetaKit is a website through which persons can complete an online sexual health risk assessment and obtain sexual health services. To be eligible, persons must be 16 years of age or older and live in Canada; they also need to have sexual or drug use risk factors for the acquisition of sexually transmitted infections (STIs) and/or HIV. To participate, persons needed to create an account on the website and complete the online risk assessment questionnaire which inquired about demographics (race/ethnicity, sex/gender, sexual orientation, country of birth, age), risk behaviors (sex and drug practices, sex work), and sexual health history (prior STI/HIV testing, prior STI/HIV diagnoses, use of HIV PrEP). Using this information, GetaKit's automated algorithms would follow extant clinical care guidelines and recommend STI/HIV testing services, which participants could opt in/out of. The goal for GetaKit was not to provide unrestricted access to HIVSTs, but rather to distribute them according to healthcare guidelines. GetaKit, moreover, sent automated reminders for persons to voluntarily report their results and then would provide targeted information based on the reported result (i.e., for treatment, prevention, or retesting). If a participant chose to report their HIVST result, they could choose from the following list of results: 'positive', 'negative', 'invalid', 'the kit was damaged', 'my kit did not arrive', 'something went wrong', and 'I prefer not to report'. This project launched as a pilot in Ottawa in June 2020 and expanded to include BlackCAP in Toronto on April 1, 2021. GetaKit became available Ontario-wide in July 2021.

Qualitative methods

In late November 2022, a focus group was conducted with GetaKit participants who had received their HIVST from the community partner

BlackCAP. Nine individuals, all identifying as ACB GBM, and between the ages of 25 and 45, participated in the focus group. All participants were invited to participate via the contact information they had previously provided to GetaKit, detailed above, as well as their past involvement with BlackCAP. In line with an explanatory sequential design (Creswell & Plano Clark, 2018), the questions posed to participants were from a semi-structured schedule, informed by the findings found in the quantitative arm of the study, presented below. To make sense of the focus group conversation, specifically as it related to the unanswered questions uncovered in our earlier work, a combination of deductive and inductive analyses was used (Creswell, 1998; Merriam, 2009). Such an approach allowed for us to center the underexplored areas which had emerged through the primary inferential statistical analysis of the quantitative data, as well as possible explanations that existed within the existent literature, such as the impact of resiliency, while also allowing for new themes to emerge based upon the experiences described by the participants. For reasons of confidentiality, all the names of focus group members reported herein are pseudonyms.

Results

Quantitative

As an expansion on the data we have previously published upon (O'Byrne et al., 2023), and which formed the basis for the qualitative work outlined below, from April 1, 2021 to May 31, 2024, 14,519 risk assessments questionnaires were submitted on GetaKit. From this sample, 14.7% ($n = 2130/14,519$) were from participants who identified as ACB, of whom 55.1% ($n = 1174/2130$) reported being male; this figure is representative of both cisgender and transgender individuals. For sexual orientation, 57.7% ($n = 677/1174$) of these orders from ACB male participants reported being GBM. This means that ACB GBM accounted for 4.7% ($n = 677/14,519$) of all GetaKit orders and 31.8% ($n = 677/2130$) of orders from ACB GetaKit participants. These ACB GBM had an age range of 16-68 years, with a mean age of 33 years and a median age of 32 years. Only 33.9% ($n = 218/643$) of ACB GBM participants reported that they were born in Canada.

For these orders from ACB GBM, 7.3% ($n = 47/644$) reported injection drug use and 6.8% ($n = 43/630$) reported sex work. As well, 16% ($n = 103/645$) reported having symptoms that were compatible with a possible sexually transmitted or HIV infection and 6.3% ($n = 40/635$) reported that one of their sexual contacts from the preceding 4 weeks had been diagnosed with a sexually transmitted or HIV infection. For testing histories, 29.3% ($n = 178/608$) of these orders were from participants who indicated that this was their first time seeking testing. Among those who had previously

undergone testing ($n = 430$), 27.7% ($n = 119/430$) reported a prior STI diagnosis. For timing of last testing, 70.5% ($n = 303/430$) indicated that their last HIV test was performed within the preceding 12 months, while only 57.2% ($n = 246/430$) of these participants reported that their last STI testing was within the preceding 12 months. Lastly, 6.7% ($n = 42/626$) reported using HIV PrEP. It should be noted that in some cases data is missing from each subcategory, due to self-reporting.

For HIVST outcomes, 52.2% ($n = 302/578$) reported a test result back to www.GetaKit.ca. Of all tests that were reported upon ($n = 302$), 75.8% ($n = 229/302$) were reported as negative, 16.8% ($n = 51/302$) as invalid, and 6.2% ($n = 19/302$) as prefer not to report. Another 3 self-test results were reported as positive (all confirmed by serology), yielding a positivity rate of 0.9% (compared to the provincial positivity rate of 0.1% in Ontario) (Ontario HIV Epidemiology and Surveillance Initiative (OHESI), 2023).

These results reinforce and expand upon our previous work published in 2022. Whereas ACB communities account for only 10.8% of HIV blood tests done in Ontario, a figure that has decreased since 2018, they account for 14.7% of all testing done through GetaKit (OHESI, 2024). In combination with the fact that nearly a third of ACB GBM who accessed testing were first time testers, this suggests that HIVST continues to be a great success in enabling testing for ACB communities. Despite this, it does not address why ACB GBM have opted for HIVST with such fervor, especially given their inferred reticence for more traditional, in-clinic, methods of HIV testing. Further, the issue remains that while we know ACB persons are accessing HIVST at high rates, most of these tests continue to go unreported, especially when compared to White participants, making it impossible to accurately monitor the tests' results and provide links to further care services (i.e. PrEP). It is these two questions which the qualitative arm of this work seeks to address.

Qualitative

In line with an explanatory mixed methods study design and deductive-inductive methods of analyses, focus group questions were prepared and interview transcripts analyzed based upon our quantitative data results, themes already found in the literature, including both individual and community resiliency, and the views and feelings expressed within the transcripts themselves. In using this approach, it was discovered that ACB GBM have complex, and at times conflicting, views regarding their use of HIV testing and reporting; a finding in line with other studies around the topic (Frye et al., 2021; Nel et al., 2013; Odhiambo et al., 2023; Spielddenner & Castro, 2010). Here, these results are broadly presented as they relate to

the research questions: the first, explaining some of the reasons ACB GBM gave for their use of a HIVST, and the second, explaining why ACB GBM were reluctant to report their results. This is followed by a discussion that relates these findings to the theme of resiliency, explicitly outlining how the various factors which led ACB GBM to make use of the HIVST can be seen as representative of a high degree of both individual and community resiliency, while, somewhat paradoxically, can also threaten to undermine that same resiliency.

Why an HIVST?

One of the most common discourses that emerged around why the ACB GBM in this focus group chose an HIVST over more traditional – that is clinical – HIV testing methods, was rooted in ease and convenience. Aaron shared that the greatest driving force for him to use GetaKit over other forms of testing was “because it was easy” to access, describing it as “much easier to do on my own than going somewhere public”. Christopher echoed this sentiment, noting that GetaKit allowed ACB GBM to receive HIV testing without having to overcome “the inconvenience of going to a public place”, and Sean reported similar feelings when he reported that:

For me, when I ordered GetaKit, it's more convenient. Because if you're going to go to [name of a sexual health clinic], or those things, the line is so long, or you have to make an appointment. And then sometimes the appointment is so long. When you can order it at home, it's at your level, you do your testing and based on the results, you know.

In all the above excerpts, the men assert that what makes GetaKit such an appealing tool is its relative propinquity; users can have the HIV test delivered to their home, use it, and gain instantaneous results in a manner far more relaxed and, as Sean notes, potentially faster, than if they were to visit a more conventional clinical setting. This may be why several of the men who comprised the focus group commented that HIVST represented their preferred way to access HIV testing, seeing it as a natural progression that was part of “everything being decentralized. You have your hybrid zoom and you do stuff in the privacy of your own home. Why not [HIV testing]?”

Recentring the experiences of the ACB community, participants also noted that, in addition to convenience, one of the chief reasons why they viewed an HIVST as a preferred method to access the HIV care continuum was rooted in the shared experiences of the community itself; ACB GBM viewed themselves as distinct, and having separate concerns, from more hegemonic populations of GBM, namely those who identified as White. For example, Montrell, when asked about the ability to access HIVST and

have them on hand both for personal use and potentially to share with others, noted that:

I should be able to get [an HIVST] for a friend or two in the Black community. In the Black community, people are very particular on HIV ... So, I can have that, I can provide, maybe even it's like a friend who doesn't want to interact with the system so that their information gets out. I'm cool with that.

Montrell, as well as others, consistently voiced the idea that HIV was a “community infection” and one that should be “managed by the community”. Even those individuals who had concerns around reporting their results to GetaKit, a topic which will be examined in greater detail below, expressed that they would be more comfortable if they were reporting to an individual within BlackCAP. For instance, Khalil stated that:

[Somebody] might not want to go to a doctor, they might not want to report online, they might be more comfortable with a peer. And so, they might connect with them. Wherever the peer might be able to facilitate, like doing the test, knowing what the result is, providing the support, and reporting.

In line with the discourse on community resiliency, the men who participated in the focus group indicated that part of the reason why they chose HIVST was because it allowed for the ACB GBM community to support one another in ways which other avenues to care did not. In contrast to more traditional HIV testing methods, Christopher noted that GetaKit “empowers us”.

Overlapping with some of the sentiments already explored around the idea of HIV as an issue with unique status within the ACB GBM community, several of the men expressed that they sought out GetaKit because it allowed them to learn their status without having to interact with the larger medical complex or run the risk of encountering acquaintances within a clinical setting. For instance, when talking about why he chose to use GetaKit, Christopher noted:

The inconvenience of going to a public place, and maybe a network of somebody that you know, in there, we're doing the testing or doing the counseling, that they're a little bit uncomfortable. But if you can do it in your own privacy of your home, knowing the results of yourself or your partners, then I'd be 10 times more comfortable testing myself instead of going out there and doing it in front of somebody. So, there's a great incentive.

Talking about his own reason for choosing GetaKit, Jay reiterated this, stating that going to a clinic to get tested was “nerve wracking, because you're the one nobody can notice ... what if this is the day it shows positive, and you don't want to be all sensitive or emotional.”

This fear that one may be seen accessing testing services or that their status may become known within the community went beyond simply using in-clinic testing. When asked whether they would make use of HIVST if

the test were obtained through a pharmacy rather than delivered to one's home, many of the men indicated that they wouldn't, with one stating: "I wasn't going to go to the pharmacy, because you have persons at the pharmacy, because they don't want nobody to know their business". Relatedly, when asked whether they would want to see HIVST offered through vending machines, similar to how COVID-19 tests and related paraphernalia was available at subway stations during the height of the COVID crisis, Ekon commented that this was a great way to increase access so long as "you don't have to go to ask or interact with anybody, you can just go pick it up yourself and move on."

This sample of excerpts illustrates that ACB GBM are more than willing to adopt the use of an HIVST to learn their status and recognize it as an important, and in some cases preferable, way to access the HIV care continuum. The findings here provide an explanation of the quantitative work presented above and published upon previously (O'Byrne et al., 2023): ACB GBM make use of HIVST kits because they view them as an easier and more convenient way to access testing. Moreover, the views expressed by Montrell and Khalil highlighted that an HIVST is seen as a tool which enfranchised not only individuals, but also the wider ACB community, to take greater control of their health and unfettered them from systems which may be seen as overly oppressive.

Why not report?

While the pericopes shared above help to illustrate why ACB GBM have a high rate of participation in GetaKit, they do little to explain the disjuncture that occurs between test use and test reporting. Of the 190 HIVSTs obtained by members of the ACB community between April 1, 2021 and January 31, 2022, results for 48% of these tests were not reported (O'Byrne et al., 2023), a statistic which has remained fairly consistent in more recent analyses. Such figures are concerning for several reasons. First, the GetaKit system only provides referrals for PrEP after a reported result, meaning that a lower rate of ACB GBM are receiving this information compared to their White counterparts, despite the fact that ACB populations account for a far higher rate of new HIV infections in Ontario (O'Byrne et al., 2023). Additionally, there is the somewhat pragmatic issue that a test which is not reported is, for all intents and purposes, unaccounted for: it is impossible to say whether these tests yielded a negative, positive, or inconclusive result, or if they were even used. Such realizations can be disturbing from a public health perspective when one considers that there is a possible trend (and anecdotal evidence reported to us) that some individuals read inconclusive results as synonymous with negative ones, despite engaging in

behaviors which put them at increased risk of sexually transmitted blood borne infections (STBBI) (O’Byrne et al., 2023).

Considering these realities, one of the aims of the focus group was to better understand why ACB GBM would sign up for GetaKit, ostensibly conduct a HIVST, but choose not to report a result. All participants discussed that the reason for this disjuncture was related to negative feelings around privacy and confidentiality, in many ways the “other side of the coin” to the more positive sentiments immediately presented above that helped to explain why ACB GBM chose an HVST.

When asked why he didn’t report his results, Sean noted that “GetaKit gives you the opportunity to uphold your privacy. So, I don’t wish to be on that website, to participate.” Sharing similar sentiments, a number of participants expressed that having to report their results to GetaKit was “no good for me”, with one participant, Dayne, stating that he didn’t report because “I want to keep [the test results] private, I just don’t want nobody to know, I can seek help on my own, or from someone who I trust.”

Many of the men participating in the focus group viewed the follow-up phone call from GetaKit staff/community partners, which takes place after one has successfully obtained a kit but not logged their results, as a breach of their privacy. Aaron expressed that the act of receiving follow up communications about logging his results gave him the sensation of “being tracked and being monitored”, stating:

If I do [the test] in my bathroom, it’s my business, give me the number, just give me the number, or I’ll call BlackCAP, or call 911. Don’t call me to ask me if I did my test. It’s none of your fucking business... Don’t call me. If you call, I’m going to hang up. I got my results, I will deal with it on my own, on my own way, no matter what.

Aaron’s feelings were largely answered with sounds of agreement from other focus group members, with some putting forward the position that the reporting of results, as well as any kind of follow-up communication, should be optional. “When you get GetaKit, they should ask you, would you like a call, text, or email within two to three days about your results”, noted Ekon, “I can give you the option to call me if I want help, to get it. Also give me the option to keep it private.”

The narrative that emerges here is one in which there is a preoccupation with privacy and confidentiality. On one hand, this can be seen as a driving force for why ACB GBM have adopted the use of HIVST to know their status at such high rates: ordering a test online negates any opportunity for a potentially stressful encounter with one’s peers, or for interaction with clinicians. In almost all jurisdictions in Canada, HIV is a reportable infection, and a positive blood-test result must be reported to a public health body. Canada also has a complex history of HIV

criminalization that disproportionately impacts people of color, which underscores the sentiments described in the focus groups regarding reporting their results to GetaKit. Of note, the HIVST does not meet ‘case-definition’ and therefore results from these devices are not reportable to public health. This may encourage the perception of the HIVST as a safer way to get tested since it does not involve monitoring by the state. Further, we know that there remains a great deal of stigma around HIV, with even the act of testing being highly stigmatized within some communities and leading to ostracization (Block, 2009; Frye et al., 2021; Odhiambo et al., 2023). This helps to explain why nearly half of the kits ordered by ACB GBM through GetaKit were never reported, as the act of logging one’s test results would be antithetical to the privacy which the HIVST affords in the first place.

A road to resiliency. The findings outlined above reflect the various ways in which ACB GBM interact with services like GetaKit and their conceptualization of an HIVST. The examination of such narratives helps explain why this community, and perhaps ACB populations more generally, have adopted the use of an HIVST, seeing it as a tool which is convenient, empowering, and which allows greater degrees of perceived privacy than more conventional testing mediums. The experiences shared by these men also help illuminate their various misgivings around HIVST and provide an explanation for the low levels of reporting, namely a concern rooted in the same considerations around privacy which initially led them to the self-test in the first place. Moreover, while not directly related to the questions which this study hoped to answer, the reports these men gave shed light on their concerns around how an HIVST may be misused and their autonomy violated. While these areas may appear dissimilar, they are all worth considering through the lens of resiliency.

In citing their reasons for testing and for not reporting, the men continuously stated the idea that HIV was an issue with special significance for the ACB GBM community, to the point where it should be dealt with, almost exclusively, by community insiders. For example, when probed about receiving follow up phone calls from GetaKit, some participants expressed that the follow up should come directly from a worker at BlackCAP, and that ACB GBM should be allowed to acquire multiple tests at once so that they could distribute the HIVSTs to other community members who may be uncomfortable accessing the test themselves. In this way, access to an HIVST was seen as increasing community autonomy and resiliency, leading to “safer experiences” that would allow men to “satisfy their curiosity” while liberating them from having to access the conventional medical system.

In this regard, GetaKit and the concept of an HIVST is a roaring success. As other studies have found, there exists a strong positive correlation between a sense of shared community, the establishment of community resiliency (in this case, resiliency against more conventional medical systems and the discriminatory practices, either real or perceived, found within), increased self-efficacy, and positive health outcomes (Bhattacharya, 2003; Liu et al., 2025). For ACB GBM specifically, studies have found that a sense of community, specifically being part of the ACB community, is linked to higher rates of HIV testing, better adherence to HIV care, in the case of a positive HIV test result, and a decrease in comorbidities and other widespread syndemic issues within the wider ACB population (Bogart et al., 2013; Medina, 2009; Reed & Miller, 2016; Town et al., 2024). Given the work presented here, it is possible to make the claim that the use of an HIVST is not only a symptom of, but perhaps can help to foster, ACB GBM community resiliency.

Despite this success, there are reasons for concern. As noted in the literature, while distrust of outsider influences is a form of resiliency, it is one that must be carefully balanced, especially as it pertains to the relationship between individual and community resiliency, and individual interactions with the medical system (Reed & Miller, 2016). In a lively exchange about the number of kits that one should be able to acquire at a time and whether the HIVST should be more widely accessible, one participant remarked: “to have this tool [the HIVST], with the level of damage it can do, to be so free and accessible might cause... damage.” When probed to expand on what he meant by “damage”, the participant expressed a fear that an individual could conduct the test on them while they were sleeping, learn their status, and share it with the wider ACB community without their knowledge. This sentiment was quickly supported by others, with Montrell stressing that such concerns were “not ridiculous” and that he was aware of an individual coercing their partner into using the test, whereby: “[she] got GetaKit. One of her and one for her partner, because she didn’t trust her partner. Second one for him. So that when he’s out of the country, she can test him when he comes back.” This was met with murmurs of agreement from several men who expressed hearing of similar situations and who shared similar concerns regarding the test’s potential misuse. In these instances, what was communicated was a general distrust of other community insiders and of their less than scrupulous use of the HIVST. As noted in other studies, there exists a link between mistrust, a lack of individual resiliency, and a decrease in self-efficacy, all which trend toward negative health outcomes (Reed & Miller, 2016; Town et al., 2024). In short, while the test is seen as liberatory to some, its potential misuse threatens the individual resiliency of others.

Unfortunately, the potential for the HIVST to be misused goes beyond individual interactions and has also colored the ways in which ACB GBM may interact with the wider medical complex. Again, discussing the potential to acquire multiple tests at once, several men shared that the ability to test multiple times a day, or immediately after a sexual encounter, made them feel “safer” and “more comfortable”, viewing the restriction on test access to be an oppressive measure:

The kits should be available to satisfy my curiosity. If I’m positive or not. If I want to take the test every 10 minutes to satisfy my curiosity. So, if I want to take it, I can. I can take one every 10 minutes, or every day. I should be able to do that. If I’m not able to do that than what is the sense in having the kit to begin with?

When it was pointed out that doing a test every 10 minutes or testing one’s partner immediately upon their return from a short trip would be unlikely to yield any worthwhile information - due to the HIVST’s sensitivity in detecting HIV antibodies and the latency period of the virus itself - this position was quickly challenged by several participants. Instead, the men in the focus group shared the opinion that such a behavior was important because of the reassurance it provided, and the perceived “need” for widespread, high frequency testing in order to benefit the community as a whole, even if such practices would run contrary to best testing practices. While such sentiments were paired with a general malaise regarding having to interact with the wider medical system, they do exemplify an overwhelming, perhaps misplaced, degree of trust in the validity of the test itself.

In this instance, the distrust of the medical system, to the point where individuals are unwilling to appreciate some of the realities of the tests limitations, can be read as a maladaptive form of resiliency. As repeated in the literature, while miseducation about sexual health practices is often conceptualized as a syndemic issue which impacts individual resiliency, if such negative actions are practiced on a wide scale, it can undermine the resiliency of entire communities (Reed & Miller, 2016).

Summary & discussion

The findings outlined above reflect the various ways in which ACB GBM interact with services like GetaKit and their conceptualization of the HIVST. The examination of such narratives helps explain why this community, and perhaps ACB populations more generally, have adopted the use of the HIVST, seeing it as a tool which is convenient, empowering, and which allows greater degrees of perceived privacy than more conventional testing mediums. The experiences shared by these men also help illuminate their various misgivings around the HIVST and provide an explanation for

the low levels of reporting, namely a concern rooted in the same considerations around privacy and autonomy which initially led them to use self-testing. Both of these findings can be seen as proof of a community which is highly resilient, making use of a new technology in order to address the perceived shortcomings of the biomedical system, leading to higher rates of testing among ACB GBM, albeit with some concerning caveats; in short, this work has shown that ACB GBM desire to be tested, unburdening themselves from a paternalistic medical system, but that the pathways and practices around testing are, in their current state, imperfect.

It is this combination of a public health system which demands self-efficacy, a trait positively correlated with individual resilience, and a deep-seeded distrust of this same system and how community members use it, a trait which undermines this same resilience, that gives rise to one of the major tensions reported upon by the men in the focus group. Influenced by public health initiatives which encourage individuals to take greater control of their own health vis-à-vis tools like HIVST, ACB GBM have readily adopted at-home testing and internalized this individual responsibility to a profound level: they reported not wanting any form of engagement from GetaKit. Yet, primarily due to concerns around privacy, the participants were not in fact using the test in the way in which it was intended, thus barring them from the very health services the test is meant to link to: if an individual uses GetaKit and logs a negative result, they are given access to PrEP resources and reminders about when to repeat HIV testing (whether outside the window period or for rescreen purposes); if the result is positive, they are given access to HIV treatment; if the result is inconclusive they are sent another test. In all of these situations, the linkage to care which HIVST affords is conditional upon results being reported; in short, GetaKit is a Faustian bargain that demands a willingness to interact with the various clinical and public health systems that one was potentially trying to avoid in order to access additional levels of health care.

This point is significant for several reasons. Focusing exclusively on the men in this focus group, it can be definitively stated that those who did not report their results to GetaKit did not really interact with the HIV care continuum. To expand upon this, it can also be argued that an individual who purchases an HIVST from a pharmacy or other provider, conducts the test, but does not report the results to a clinician, has also not interacted with the HIV care continuum in any meaningful way. Given this consideration, the experiences reported upon by the men in the focus group can be seen as further evidence for conclusions drawn elsewhere: an increase in HIVST does not in fact equate with greater linkages to care or increased access to sexual health resources in the form of PrEP, PEP, ART, or STBBI information (Adeagbo et al., 2024).

In the context of ACB populations and ACB GBM being disproportionately burdened by ongoing HIV transmission, we thus challenge the supposition that HIVSTs will naturally equate to improved HIV prevention for these men. The HIVST is a tool, but one that is fraught with shortcomings - and which consequently should not be peddled to equity-deserving populations as a panacea for HIV. Instead, work is required to determine how and in which ways we can maximize the benefits of HIVST for ACB communities and ACB GBM (e.g., privacy, convenience), while minimizing its shortcomings (related to concerns about reporting and subsequent non-engagement in the HIV prevention, care, and treatment cascade). For actual prevention to occur, ACB GBM need to be linked with PrEP and with treatment (to achieve U=U). Until such time, the HIVST may foster a false sense of security (when used as described above) and paradoxically put people at higher risk for HIV acquisition than had they sought out testing via traditional clinic routes and pathways. Without linkage-to-care and education about the importance and value of linkage-to-care, mass deployment of the HIVST may inadvertently increase harm - especially when it was being used as described herein. Future guideline development needs to better incorporate community perspectives and dissemination to maximize uptake.

Conclusions

GetaKit, and HIVST, as a purported pathway to care, is not the solution to the rising rates of HIV among ACB GBM in Ontario. Although ACB GBM appear willing to use HIVST, viewing it as both convenient and empowering, they are not, due to concerns around privacy, willing to report their results. This restricts their ability to access the healthcare resources that would actually have an impact on HIV transmission. Furthermore, the kinds of test misuse and lack of education around HIVST and HIV, exhibited in the excerpts shared here, inhibits programs like GetaKit from reaching their full potential and undermine the opportunities for greater resiliency and capacity building among ACB GBM. This suggests a need for change. First, it is clear that connecting users to HIV prevention services, and related resources must not be conditional on the reporting of results; for example, information on PrEP, PEP, and related HIV prevention strategies can be offered at the time individuals acquire the HIVST, rather than after its use. Second, considerations must be made regarding what the actual purpose is of HIVST and how it is intended to be used; as has been evidenced, most of the men in the focus group did not actually perceive HIVST as a linkage to care, nor did they want to be linked to care. For many men, the test was a tool that was to be used and discarded,

and the results, whatever they may be, were not viewed as something worth sharing. Relatedly, this indicates the need for more concerted efforts around HIV education and increasing the sexual health literacy of ACB GBM to ensure a greater willingness to access care and, hopefully, less test misuse; we must focus on strategies that increase both individual and community resiliency and efficacy, while minimizing those elements which undermine it.

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