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'You're only there on the phone'? A qualitative exploration of community, affect and agential capacity in HIV self-testing using a smartphone app

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Abstract

Mobile health (mHealth) technologies for HIV care are developed to provide diagnostic support, health education, risk assessment and self-monitoring. They aim to either improve or replace part of the therapeutic relationship. Part of the therapeutic relationship is affective, with the emergence of feelings and emotion, yet little research on mHealth for HIV care focuses on affect and HIV testing practices. Furthermore, most of the literature exploring affect and care relations with the introduction of mHealth is limited to the European and Australian context. This article explores affective dimensions of HIV self-testing using a smartphone app strategy in Cape Town, South Africa and Montréal, Canada. This study is based on observation notes, 41 interviews and 1 focus group discussion with study participants and trained HIV healthcare providers from two quantitative studies evaluating the app-based self-test strategy. Our paper reveals how fear, apathy, judgement, frustration and comfort arise in testing encounters using the app and in previous testing experiences, as well as how this relates to care providers and test materials. Attending to affective aspects of this app-based self-testing

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practice makes visible certain affordances and limitations of the app within the therapeutic encounter and illustrates how mHealth can contribute to HIV care.

KEYWORDS

affect, care, digital health, HIV, mHealth

INTRODUCTION

Mobile health (mHealth) technologies, such as smartphone applications (apps), for HIV care are developed to provide diagnostic support, health education, risk assessment and self-monitoring. These technologies are developed to improve an existing therapeutic relationship between a patient and their provider or to replace part of this relationship. Part of the growing emphasis on mHealth for HIV care includes the development of apps for HIV self-testing. Current research often focuses on the potential applications and functions of mHealth technology for HIV care (e.g. self-testing and self-monitoring) (Muessig et al., 2015; Schnall et al., 2015; van Heerden et al., 2017; Zhao et al., 2018), but part of what makes a therapeutic relationship work (or not work) is the emotional aspect of that relationship. HIV self-testing is an emotional experience (Chiou et al., 2019), and there are persisting concerns around the potential lack of emotional support available during HIV self-testing (Ritchwood et al., 2019). Yet, despite the acknowledgement of the emotional nature of testing, and the continuously emerging role of mHealth in the realm of HIV self-testing and care, there is little attention paid to the affective dimensions of mHealth in HIV testing, how this relates to people's feelings and emotions, and how this relates to the use of smartphone applications in HIV testing.

In recent critical work on food tracking apps, Deborah Lupton explores different situations in which apps are used, what the technology invites or allows the user to do (affordances), the feelings and emotions that are evoked, and how this relates to if, when, and how an app is used (Lupton, 2018). She looks at how humans and apps come together in instances which generate greatly varying 'agential capacities' and 'affective forces' (Lupton, 2018). Agential capacity is a term used to signify; 'the ways people create meaning and action with nonhuman objects' (Barad 2007 and Braidotti 2016 as cited in Maslen & Lupton, 2018: 2). This means that technologies, along with their affordances, come together with a person (user) in situations that generate different meanings and opportunities for action. Meanwhile, affect can be referred to as the force that evokes, creates and brings about individual experiences of feelings or emotion (Tucker & Goodings, 2017). The creation of feelings, meaning and action is a relational process, with each involved actor having agency (Lupton, 2019: 127).

Lupton's work provides a broad foundation for critical work on digital health apps highlighting the complex conditions in which technologies and people come together and shows that the agential capacities and affective forces generated by human-app assemblages are subject to change and dependent upon the situations in which they arise (Lupton, 2018). Furthermore, she shows how affective forces can

contribute to app use or non-use (Lupton, 2018). Care practices involve the mixing of humans and non-humans and care is relational, collaborative and material (Singleton & Mee, 2017). The materials which help constitute practices of (routine) care bring with them, and bring about, affect and emotion (Buse et al., 2018).

The vast majority of research exploring digital health and affective relations, and those that have focused on HIV care, have been geographically confined to Australia and Europe. Here, we argue that to gain a deeper understanding of how relationships between people and mHealth technologies develop and how/whether these new technologies come to work in providing care, we need to look at affective dimensions of mHealth-based self-testing in different settings. HIV testing includes materials such as blood-based testing kits, test protocols and healthcare facilities. However, these things and their histories differ between contexts. In this paper, we explore the use of a novel app-based HIV self-testing strategy in Cape Town, South Africa and Montréal, Canada. We contribute further to the literature on mHealth and affect by focusing not just on the app itself, but also on how it becomes part of self-testing in relation to the other materials and routines in the diagnosis of HIV.

In order to understand the use of mHealth for HIV self-testing, it is important to first explicate some of the historical and material differences in HIV services between the Canadian and South African context. Briefly outlining these contextual considerations introduces the communities and infrastructures with/in which the app works. In Canada, the AIDS epidemic initially disproportionately impacted gay men and men who have sex with men (MSM). The strong presence of middle-class white men in the gay community brought political influence that was uncommon for a marginalized group (Epstein, 1996). This is significant as these '[...] communities had political skills and access to funding, and used both community self-help and political advocacy to generate successful responses'. (Merson et al., 2008: 483). This group came together and mobilized their resources, creating a community for themselves in which specialized care services, such as the establishment of clinics specialized in HIV/AIDS care, emerged. In contrast, socioeconomically vulnerable populations in South Africa had fewer political and financial resources to draw upon for organized community responses, which was further compounded by the lack of attention to the growing HIV/AIDS crisis during the late 80s and early 90s as South Africa fought against apartheid rule (Merson et al., 2008; Simelela et al., 2015). Later on, factors such as South African President Thabo Mbeki's denialism around HIV and the connection between HIV and AIDS led to further challenges for civil society as they pushed for attention and service provision around HIV/AIDS (Simelela et al., 2015). These factors contributed to a rapid increase in South Africa's HIV prevalence rate in an already resource-constrained healthcare system. Differences in HIV responses in these two contexts are apparent.

Furthermore, different HIV testing guidelines and approaches are used in these two settings. Although the rapid point-of-care (POC) test for HIV was approved by Health Canada in 2005, the Canadian HIV Screening and Testing Guide provided by the Public Health Agency of Canada (PHAC) states that 'The majority of healthcare venues carry out "standard" HIV testing' (PHAC, 2012: 27). Standard testing involves collecting a vial of blood, which is then sent to a laboratory for testing. Test results are typically available after 1 week. This differs from POC testing for HIV, which is not regarded as a standard or conventional mode of testing for HIV in Canada, though some sites serving 'high-risk' groups have POC tests available (PHAC, 2012). In contrast, in South Africa it is standard practice to perform rapid POC HIV tests for the purpose of diagnosis (Department of Health: Republic of South Africa, 2016; Engel et al., 2017). The use of different materials in each environment (i.e. laboratory testing, rapid-blood test etc.) is part of the HIV testing experience. The app investigated in this paper requires the use of a separate physical test (an oral rapid test).

mHealth applications promise to replace part of or improve existing therapeutic relationships. During HIV testing, interactions between patients and human healthcare providers usually occur while

doing the test, waiting for the result, and interpreting the test, and may include discussion around prevention, risk behaviours and follow-up testing and care. In this paper, we explore people's interactions with human healthcare providers as well as the app and explore how feelings and actions emerge within these relationships. Similarly to human healthcare providers, an app must also work in relation to different elements of existing healthcare infrastructures and testing histories. These ongoing histories are part of the daily lives of people who test, as well as the material and discursive components of HIV testing. Thus, how people work with a new app in the practice of self-testing, and how testing situations unfold, are coloured by context. We use the concepts of agential capacities and affect to investigate how meaning, action and feelings are generated through the situations and practices in which people interact with a novel smartphone app called HIVSmart!, which was designed to support HIV self-testing and care in Montréal and Cape Town. We aim to explore 1) how affects and agential capacities emerge as testers and the app work together during the process of HIV self-testing and 2) the implications of this for how this app might play a role in HIV testing/care practices in different settings.

MATERIALS AND METHODS

Recruitment and data collection

Study participants recruited for this qualitative study came from two quantitatively based studies: one in Cape Town, South Africa (Pai et al., 2018), and one in Montréal, Canada (Pant Pai et al., 2018). The quantitative studies aimed to evaluate an app-based HIV self-testing strategy (HIVSmart!) designed for use alongside an oral HIV test. This paper is based primarily on observation notes, 30 semi-structured interviews with study participants from Cape Town and four semi-structured interviews with study participants from Montréal. Due to time constraints and because the quantitative study in Montréal had already ended, only a small number of study participants were available for interviews. However, although this number of interviews does not constitute thematic saturation, they provide key insights regarding the Montréal context as well as the use of HIVSmart!. By including these interviews, it also provides an opportunity to look at the differences and similarities in testing processes in different contexts. These interviews were part of a larger study which also included three semi-structured interviews with nursing/medical staff from the study in Cape Town, four semi-structured interviews with healthcare staff who worked on the study in Montréal, and one focus group discussion (FGD) with three nurses and three healthcare workers in Cape Town (a total of 41 interviews and 1 FGD). For further details on the content and themes covered in the interviews and FGDs with patients and study staff, please refer to our previous publication (Janssen et al., 2020). Although the data collected from study staff are not the focus of this paper, the interviews, FGD and informal discussions with study staff informed our view regarding the app in each context as well as provided contextual and background information regarding the patient populations and clinics described in this paper. The nurses and healthcare workers who worked on the study typically had around 10–15 years of working experience in the field of HIV.

In South Africa, oral self-tests were approved by 2016, so participants were able to take them home. Participants in the Cape Town based study were offered the choice to complete a multilingual version of the app-based self-testing strategy unsupervised at home, alone at the clinic in private kiosks, or at the clinic under the supervision of a study nurse or healthcare worker. The app strategy was supervised by a healthcare provider in Canada, as self-tests were not yet approved by Health Canada at the time of the study. Participants in Montréal were offered a supervised strategy in the clinic that simulated a home environment. They were offered a tablet with the application and were

asked to complete a bilingual version of the app and self-test alone in the clinic with a nurse available for assistance and/or post-test counselling. Additional details regarding the app strategy in Montréal are available in a previous publication (Pant Pai et al., 2018). The interviews for this paper took place in South Africa in February-March 2017 and in Canada in June of 2018. These interviews were conducted at different time points in relation to the study. The quantitative data collection for the study in Montréal had already been completed when interviews took place, while in South Africa, quantitative data collection was ongoing during the time interviews were conducted. Interviews in Canada were completed in English. The interviews in Cape Town were completed in English in instances where the participant spoke English, otherwise a translator was present. Translation of answers into English occurred directly during interviews. All interviews were conducted and digitally recorded with the consent of the participant. This study was approved by Institutional Review Boards of two institutions including the McGill University Health Centre, Montreal, Canada, and the University of Cape Town, Cape Town, South Africa. For privacy and confidentiality reasons, research data are not shared.

Fieldwork approach and analysis

Data were collected using an ethnographic approach. Ethnography is a fieldwork approach which aims to understand a community and the perspective of study participants while getting a holistic view of a situation (Hennink et al., 2011). It also includes the researcher's participation in the life of the study population and aims to gain in-depth insight into the lives of the study population (Hennink et al., 2011). [RJ] spent a total of 3 months doing fieldwork within the study/clinic setting in Cape Town and 2 weeks in Montréal doing non-participant observation alongside interviews. In addition to a focus group in Cape Town and interviews with study staff in both settings, she also took part in participant observation during study team meetings in Cape Town and during informal conversations with the study team in the clinics. Consistency between interviews was ensured by the use of a topic guide. Data were transcribed and analysed using a thematic analysis approach and NVivo9 software. Codes were developed iteratively through themes that arose during transcribing and using existing theoretical literature. [AK, NE, RJ] used the concepts of affect and agential capacity to sensitize themselves to particular aspects of the interview data that centred on emotion, feelings, preference for the app or other test methods, and the meaning behind test strategies.

RESULTS

The clinic and the community – Cape Town

While interviewing participants about their experience with HIVSmart!, the interviewer [RJ] asked people about past HIV testing experiences and their interactions with healthcare providers during testing. In response, participants often spoke about past negative experiences with HIV testing and the healthcare system in South Africa. These negative experiences included things such as judgmental healthcare staff, fear of visibility in the community, long wait times and perceived indifference of healthcare providers. Participants spoke about feelings of discomfort and fear in relation to the testing process and healthcare professionals in the clinic.

“They're [students are] afraid. If you go to the clinic, and then you told the nurse that you are, you want to test, she will ask you the question; why do you want to test? So others

they don't feel right about that question. If someone tells you I want to test, you must test her, [...] because it's the thing that she want to do. Not ask her questions, no. So if it [the self-test] was on the chemist, everyone would go for it. Yes.”

(#30, Female, South Africa)

People also related fear of HIV testing to gender and the meaning of testing within the community. One participant said:

“Because, most of the time, we as men, we're scared of the, of the, going to the clinics. We're very shy going of there because in our thoughts we think, if you go there, people will think [...] you're sick or something. We're shy of that. We don't really like to be exposed to that public health.”

(#18, Male, South Africa)

For this participant, in the context of being a man in Cape Town, being seen at the clinic means that others will think he is sick. His feelings do not only relate to individuals in the clinic or HIV testing, but also to ‘public health’ services in general.

One participant stated how queuing at the clinic was a waste of time, how clinic nurses were not friendly enough, and that going to the clinic made him angry (#15, Male, South Africa). Meanwhile, another participant highlighted the lack of care he felt he received during a previous testing experience and how it related to his testing practices. The participant illustrated this saying;

“Participant: I told myself I won't do that test [HIV test] again, it's a waste of time. ‘Cause they don't even care.”

“Interviewer: Who doesn't care?”

“Participant: The nurses there in [name of place]”

(#23, Male, South Africa)

Here, we see that the perceived indifference of the healthcare provider relates to the participant disengaging from testing services. Another participant talked about her negative experiences with the regular clinic staff in contrast to nurses from the self-testing study. The participant stated;

“Participant: Um, the difference [between current and previous testing experiences]? First difference uh, the nurse from this side [i.e. nurses from the study] they are nice. Yes. They can, they can make you feel comfortable. Mm. That side no. [Interviewer says: No?] They are a little bit rough. You see? Yes. So, this side [the study nurses] um, they, the nurse that was busy with me, she was acting like my mother. Yes. So I wasn't scared. I was just relaxed. [...]”

(#30, Female, South Africa)

The study evaluating HIVSmart! provided its own healthcare staff. These nurses and healthcare workers were separate from regular clinic staff and focused specifically on providing support around HIV self-testing. This allowed for juxtapositions between healthcare providers to arise.

The above examples demonstrate how some people feel judged, exposed, scared and frustrated due to the HIV testing services provided within their community. These services and experiences are

historically grown from an overburdened healthcare system that lacks resources and provides general services in a population with a high HIV prevalence. These comments are important to consider, as they shape and give context to people's experiences using HIVSmart! in Cape Town and how the app provides care and inspires particular feelings.

The app in Cape Town

As we saw in the previous section, negative experiences with the healthcare system, care providers and the community contribute to people's feelings of fear and discomfort, reluctance to test, and the meanings attributed to the testing process and healthcare services within the community. Here, we explore how HIVSmart! works together with study participants during the self-testing process, how this relates to past experiences, and how feelings and emotions emerge during this process. HIVSmart! was designed to provide support for patients in different ways. For example, it includes a video that shows the user how to conduct the oral self-test and provides a guide on how to interpret test results. In addition, the app provides information about HIV and HIV transmission and includes an HIV risk assessment with several questions regarding a person's sexual behaviours, condom use, alcohol and drug use etc. One participant referred to the kinds of questions the app posed around HIV risk behaviours, and the importance of these questions. She talked about how the app asked her questions that she thought would never have been asked otherwise. This speaks to the limited care many people experience during regular testing.

“But, it, it opens up your mind to a lot of things that you take for granted – to a lot of things that you're like, yeah well whatever. You know? And also yourself, you tend to assess yourself as a person. Had that app not, had I not been asked those questions, I don't know if anybody would have asked me those questions. So, if my results came out negative, I would still have, [...] I would have still been able to remember those questions and sort of like shift and change my life into a certain direction where I can avoid being infected or anything like that.”

(#27, Female, South Africa)

Another participant echoed this remark, saying the app provided some information he had never heard before (#24, Male, South Africa). Providing information around HIV mimics the process of pre-test counselling, but sometimes, the app seems to go beyond the information that is more commonly provided in the clinic.

Although the example above shows how some participants appreciate the questions asked by the app, sometimes the risk assessment raises further questions. During fieldwork, [RJ] had an encounter with one participant who was frustrated by her risk assessment result. The participant did not believe she was at risk of HIV, as indicated in the app. The participant disagreed with the risk score provided by the app and was worried by her result as it lead her to believe that all of the app's risk score results were 'pre-generated'. After the patient left, the nurse explained to [RJ] that a potential explanation for the risk score was that the participant might only have sex with her partner, but might have also indicated in the app that they do not use condoms. It might make sense that you would not use condoms with your spouse/monogamous partner, but the app is programmed to identify this as a risk. This encounter lead [RJ] to reflect on the fact that the app has limited ability to communicate with the tester and cannot enter into dialogue with the tester around potential disagreements or issues, which might

require further contextualization or explanation. As with this example, certain encounters with the app can lead to frustration, lack of trust or concern for the person testing. Importantly, however, other participants illustrated how the app mimics the role of a human care provider, but without judgement.

“Participant: [...] And you, you don't feel afraid. You just, you're free to answer the questions.”

“Interviewer: And why don't you feel afraid?”

“Participant: You know, when you are talking to a person, sometimes you are shy to ask, to answer the questions that they ask. Or you, others they ask the questions that you are not comfortable to, to, to answer. So the app, you know there is just a, a app, you're talking to a person that is there, it's their voice, so it's easy to answer the question, yes.”

(#30, Female, South Africa)

“Another participant illustrated this saying;

Yes, 'cause I'm not answering anyone. I'm just busy with the phone. Nobody's... the phone is only asking the questions, no one, 'cause I'm not answering to anyone. [...] It's only that doctor there in the phone, that is the front. Because sometimes you don't like to speak out with anyone. So that helps a lot some- with those things. You are only there on the phone, just trusting the phone.”

(#1 Female, South Africa)

The app plays two roles simultaneously in these instances. Both participants appreciated the ability to answer questions on the phone without fear of judgement as they recognized it as an app/phone and not a person. However, the first participant also referred to the app as ‘talking to a person’ and the second participant referred to the ‘doctor there in the phone’.

Although participants often highlighted the app in explaining their preference for this testing strategy, in other moments, the human healthcare providers in the study came to the foreground. One participant stated that the self-testing option was a way out because there was no one to be angry at if you do it on your own (#15, Male, South Africa). Another participant then said that the ‘new test’ (referring to the HIVSmart! strategy) was ‘fun’. However, he felt like the biggest difference between his previous HIV testing experience and the one using the app-based self-test was the way the study nurses ‘explained everything’ as well as how they ‘spoke’ and ‘did things’ (#23, Male, South Africa). This reflects the comments regarding the clinic context in Cape Town and the difference in care that participants received from the study versus general clinic services. Even though participants in the study were self-testing using the app, they still interacted with the study's nursing staff before, after and sometimes during the self-testing experience.

Against the backdrop of past negative experiences around HIV testing described by some participants, different affective responses arose from the app-based self-testing experience. In some situations, the self-testing experience was an informative and caring one, where the app generated time to consider important information and replaced the judgmental and hurried human healthcare provider. In another instance, the app's risk assessment clashed with the tester's personal view of risk, causing worry and frustration. This highlights the importance of human healthcare providers, who are able to answer questions and attend to patients' concerns. The app-based self-testing experience still foregrounded human care providers. As seen in the previous section and above, for some participants, a

feeling of relaxation and comfort emerged in the presence of a caring healthcare professional who was separate from the general clinic services. In a setting where previous HIV testing experiences evoke so many negative feelings, the HIVSmart! strategy affords people the option of avoiding parts of the healthcare system. This creates space for HIVSmart! to work, as people perceive it as informative and non-judgmental and the human services provided around the app are perceived as better.

The clinic and the community – Montréal

We also collected data from a clinic in Montréal, where they provide health services with a special focus on sexually transmitted infections (STI's), the LGBTQ community and other 'marginalized' populations (Staff Member #2, Interview). Participants shared previous HIV testing experiences from settings such as walk-in clinics and hospitals. In one example, a participant highlighted all the questions he is confronted with at hospitals or walk-in clinics that serve the general population. He pointed out feeling annoyed and judged in these settings where the healthcare providers questioned his motivations for testing. He then related these experiences to his previous actions such as delaying testing.

“Like uh, my experiences going to like a regular hospital or another walk-in clinic or things like that, they put me off to do HIV testing and STI testing. So, if I never would have come to [name of clinic], I think a product like this [the app and self-test], I probably rather do this than go and get a regular STI or STD testing. Because I would just be annoyed with the constant judgement, the constant um... like 'cause usually you go to a clinic or a hospital and you say well I would like to have an STI test. And like I said, they're always wondering are you sick? Are you feeling sick? Do you, do you need medical attention? Are you having symptoms? Those types of things [Interviewer says: Yeah]. And I can see how doing that every single time, it's even for myself, I was always like okay... maybe I'll put it off for another week before I actually go and get tested 'cause it's not, I'm not emotionally ready for this right now.”

(#4, Male, Montréal)

This is similar to some of the experiences from participants in Cape Town who described feeling judged during testing. Unlike the participants we spoke to in Cape Town, however, Montréal participants were able to attend a clinic specifically geared towards the LGBTQ community. This related to comfort and decreased feelings of judgement in comparison with going to general community services (e.g. a hospital or clinic). One participant illustrated this saying;

“[...] but I don't feel like I've ever was in front of a judgy person, so [Interviewer says: Yep] um, especially here [at name of clinic] – because I mean it's all, they're all aware it's mostly LGBT people who come here. So, it's not like I went to a hospital or like a regular clinic – I'd be uncomfortable there, basically [Interviewer says: Yeah]. Like here I feel comfortable. Like, and you know, nobody's perfect, so, but I feel like most doctors and nurses are like, you know [Interviewer: Okay.] are pretty uh... I can trust them [Interviewer: Yeah.] and not feel ashamed they're like whatever etc., so...”

(#3, Male, Montréal)

Participants explained how negative experiences were part of why they chose to access testing services at a clinic that specialized in working with the gay community (#1, Male, Montréal). One participant

highlighted how the environment and community within this clinic contributed to the normalcy of his testing experience.

“So I just say I have an appointment with Dr. X and I just... so I sit, I wait and I feel totally like, like as if I was just getting, I dunno, I was gonna come in for a cold. Like for me it just feels like, like I just do everything normally – like I’m on my phone, doing, still working. I mean I even sometimes flirt with the, if there’s a cute guy and like... and to be honest, I saw my [family member] here last year. And I was like ‘oh, hi [family member].’ ‘Cause he’s gay so we’re like, he was seeing his doctor for the same, like we were just getting our routine test. So for me, it’s part of my life.”

(#1, Male, Montréal)

Again, this highlights how for some patients, this particular clinic is a place that evokes a sense of comfort and routine. However, participants also mentioned that not everyone feels comfortable going to the clinic for their testing.

The app in Montréal

One participant spoke about how the app-based self-testing might be useful for others in the community who are embarrassed about HIV testing. This participant related this to his previous negative experience going to a hospital for HIV testing and feeling judged. He stated;

“And I think if somebody could self-test, or test at home, I think it would be great for them because not everybody is as self-aware or self-confident as myself. Like, I, I, I know some friends that are super, super shy – that when they come here it’s like they wanna hide. And [clinic name] is super open for those kinds of things. So, I can only imagine that people that are like that, that would have to go to the hospital like I did, just ask for an STD or STI screening, even if they not had symptoms, would be mortifying for them.”

(#4, Male, Montréal)

This comment highlights that some people need to access services at a regular hospital/clinic as not everyone has access to a clinic with specialized services. Another participant emphasized this saying that he used to live several hours away from Montréal and, although he had hospitals in the community where he used to live, there was ‘no gay community’ (#1, Male, Montréal). Here, we see how clinic and community context might contribute to preferences for different testing methods.

Despite participants talking about the good rapport they had with this particular clinic and their current healthcare providers, convenience was also a part of the feelings that arose around the app-based self-testing process. One participant highlighted his frustration around HIV testing in the clinic due to the length of the process. He illustrated this saying;

“Um, it’s, it’s a bit of a process actually, um, and it starts with the fact that the doctor who sees me, I can’t make an appointment, I have to make an appointment every three months but I can’t make it until a month in advance because they don’t have a schedule. So I have to call. So I have to wait on the phone while I’m at work because they’re only, they only take calls during office hours. So I have to take time off work to make the phone call, wait on hold as you know with any doctor’s office that can be an issue. Once I make the

appointment I have to come in, you have to give yourself, you know, a good hour, a good two hours I should say, between making your way over here from work, um waiting, waiting, seeing the nurse, seeing the doctor, waiting in between, all that kind of stuff. Um, so it is a process and then the reason I didn't like the, the reason I prefer the rapid test is because I don't want to have to wait two weeks to know for sure what my results were. Um, so yeah so it's a long process overall.”

(#2, Male, Montréal)

When asked if the participant would use the app-based self-testing strategy again, he said yes, relating his decision to the convenience of the testing strategy. Another participant showed interest in using this method again due to the speed of the results, as the oral test provides results in approximately 20 min (#4, Male, Montréal).

Participants also liked the risk assessment in the app. However, while speaking with one of the clinic nurses about the risk assessment provided he noted;

“... but the uh people really liked to have an instant um sort of feedback about what their risk are, even though sometimes they did not agree, because they would fall automatically being high risk since they were MSM and sometimes they would disagree because they were using always protection but they were with an HIV+ person which his viral load was undetectable so there's some uh, there's some grey area.”

(Nurse, Montréal)

This is very similar to the situation described by the participant in Cape Town, who was worried by her risk score result from the app. Again, this points to the limitations of the app in its ability to interact and create dialogue with testers, but also highlights the importance of the human care providers present as they can provide further explanations to people if/when necessary.

In summary, we highlight examples that show how a clinic specialized in serving the LGBTQ community acts as a place where some people feel accepted and comfortable while testing for HIV. Yet, these specialized services are not necessarily available in every community, and even with specialized services, this does not necessarily meet everyone's needs. Clinic spaces that provide sexual and reproductive healthcare can generate feelings of community and belonging in some instances, yet also embarrassment, intimidation and anxiety in others (Wright, 2019). In places where people feel shame or fear and in instances where people feel disconnected from an accepting, non-judgmental community, the app-based self-testing could provide an alternative. Participants appreciated the immediacy of the app strategy and its risk questionnaire; yet, additional questions might still arise from the app encounter.

The test of time

One key part of the HIVSmart! strategy is the use of an oral HIV self-test. Testers must simultaneously interact with the app and self-test during the test process. This section aims to disentangle how affects emerged in the relations between the tester, the app and the oral self-test, with a focus on the temporal aspect of this encounter.

Participants often referred to two different aspects of time with regard to HIV testing and the emergence of feelings. One aspect is how feelings and emotions changed over time (i.e. from one testing experience to the next), and the other is how feelings emerged within each testing experience. Waiting for an HIV self-testing result can be nerve-wracking, inducing feelings of anxiety (Witzel et al., 2019). Part of the

affective response within a testing experience relates to the length of waiting time for test results, and what people do within this time. Rapid tests, such as the oral test used with the app-based strategy, take about 20

“And then I started to get nervous. I don't know why. I was like, now that I'm gonna know it [the result] faster, it's like, like it was a new thing for me. Like, like I'm used to like waiting two, not waiting two weeks but just knowing it's gonna take two weeks to know. But then now that I knew I was, I was like so starting to get nervous – even though I had nothing to worry about.”

(#1, Male, Montréal)

min for a result to appear. Conventional laboratory-based testing, which is an available option at this clinic in Montréal, reports results within two weeks. Furthermore, patients at this clinic can also request only to receive a response from the clinic if the test result is positive or if follow-up is necessary. For some people, testing is a routine and they are accustomed to a particular method. One participant described feeling nervous using the app-based strategy and at the same time related this to how the ‘new’ strategy differed from his normal testing routine. The participant illustrated this saying;

For this participant, the immediacy of the test result in comparison with the participant's normal test routine contributed to the emergence of anxiety during the test process. Another participant mentioned how the HIVSmart! experience differed because he did not have a nurse there to distract him during the testing process. He stated;

“Um, so [inaudible] some anxiety. Especially, you're alone right? So you don't have somebody that talks to you while, which you know, I have my nurse right now because I'm on the PrEP study and we have a follow-up every three months. So she takes my blood and then you know, does, starts HIV rapid testing. But I don't even realize it you know, because she's talking to me... blah, blah, blah. So in that room, you're alone, um all you have to think about is this right? So that sort of gets into your head.”

(#3, Male, Montréal)

Without the distraction of a nurse, the participant suddenly has time to focus on the test process, as well as time to think about different outcomes. This statement shows how the situation unfolds differently in the presence of the app, where possibilities for communication are limited. However, not all participants experienced this waiting time the same way. Participants described how the app filled the waiting time with questions (#15, Male, South Africa; #30, Female, South Africa; #29, Female, South Africa).

“[...]While you wait for the time, you just carry on with other questions. When the time is done it shows you the, the results [...]”

(#30, Female, South Africa)

But, despite there being questions to fill this time, people completed these questions at different speeds. Another participant illustrated this saying;

“Because, I did fast that thing, I'm fast, I did that thing fast. And then the 20 minutes. I think I was left with ten minutes because I was fast. And then saw, what does this mean? I didn't know. And then, there by the tablet [i.e. on the app], they didn't show me, because they will show me that there, there's they will show me those results after 20 minutes.

Of which I [inaudible] I took 10 minutes doing all that thing on the tablet. So I waited, I waited for another 10 minutes to get that 20 minutes.”

(#29, Female, South Africa)

Participants interact differently with the app. Although the app invites the user to answer questions, there are a finite number of questions in the app. Therefore, the interactions afforded by the app are limited to the questions and HIV information programmed into it. These examples illustrate how testing methods, testing routines, the role of healthcare practitioners and the app's affordances and limitations shape different temporalities within test practices and how this contributes to the emergence of feelings within the testing experience.

DISCUSSION

This study explores how an app called HIVSmart! takes on certain aspects of the therapeutic relationship and what this means for the affective dimensions of HIVST. Through this paper, we show how preference for the self-test and app, and the comfort of testing with the app, emerge in relation to previous experiences of perceived judgement while doing testing in a public clinic with a human care provider. We also illustrate how the app, while attempting to emulate pre-test counselling by a human care provider, shows care as it provides information and asks questions that might not otherwise be asked. Yet, we also see that the app is not always able to mimic a human provider, as dialogue with the app has limitations, which sometimes results in frustration or worry for the tester. These examples reflect prior HIV care research, which shows that trust and attentiveness strengthen the therapeutic relationship, while feelings of fear, discrimination and lack of communication may undermine this relationship (Gourlay et al., 2014; Ondenge et al., 2017). Feelings and meanings from previous experiences contribute to whether/how a person uses a testing method, and how/whether someone uses a particular testing method in turn contributes to how new feelings emerge. Therefore, our results reveal how affective responses and agential capacities co-constitute one another.

We also show that feelings within the app-based self-testing experience emerge as part of larger material histories in different contexts. For example, the app strategy requires a rapid oral HIV test. Although rapid testing is suggested for ‘high-risk’ populations, not all participants routinely use rapid testing in Montréal. Anxiety emerged in an app-based self-testing situation where one participant received his test result more quickly and directly than usual. Furthermore, the clinic we explored in Montréal opened during the AIDS crisis in the 1980s and is a space that caters specifically to the needs of the LGBTQ community. Due to the quick spread of HIV in urban settings at the beginning of the epidemic, HIV services in Canada appear primarily in urban locations (Schafer et al., 2017). Non-urban settings in Canada have a shortage of healthcare providers, lack HIV specific expertise, lack funding for HIV testing programs and services, and present an increased risk of stigma, isolation and fear of discrimination for patients (Schafer et al., 2017). This was reflected by some of our participants in Montréal who described previous experiences with the judgmental atmosphere of regular clinics and hospitals, and isolation from services that work with the LGBTQ community. Participants in our study pointed out that in situations where people do not have access to specialized services where they feel connected to their community or have a sense of belonging, such as those living in rural areas, the app-based strategy could play a part in creating a more comfortable testing experience.

Although our study focused on the app, our research highlights the care provided by the research nurses within the study in Cape Town. Care plays a key role in establishing good research relationships, and provision of ancillary care by research staff appears to be more crucial in places where there

is inadequate healthcare access (Zvonareva & Akrong, 2015). This was reflected in our study, where some participants in Cape Town described receiving better care from study staff compared to local nursing staff in the public clinic. Public clinics in South Africa have a high patient load and healthcare staff need to contend with infrastructure and resource constraints on a daily basis (Davids et al., 2015; Engel et al., 2017). These factors contribute to the affective responses described in our analysis. Issues in service provision leave space for the app to work, yet the app always works in relation to the other actors in the user's past and present test setting. Trained healthcare staff played an important role in supporting patients throughout this app-based HIVST strategy. Implementation of mHealth strategies for HIV self-testing should consider how healthcare staff might be involved in the self-testing process, what training they may require in order to support growing mHealth strategies for HIV care, and how they can contribute to the effectiveness of new mHealth strategies. A user is not simply 'there on the phone' as one of our participants described, they are 'there' in their past and present testing environment, with memories, a social position, with certain healthcare facilities and human resources, while using a particular testing method. This gives rise to different app-based self-testing experiences, as well as different meanings, feeling and actions evoked within the experience.

CONCLUSION

In this paper, we show that attending to the affective dimensions and agential capacities that emerge in HIV self-testing with mHealth technology helps to identify the affordances and limitations of mHealth in the therapeutic relationship. But, we also show that the affects and capacities which emerge are made and remade in each testing experience, and come about in relation to ongoing histories of individuals, communities and materials in different settings. These affects might evoke feelings such as fear, frustration or worry in some instances, or feelings of comfort, relaxation or care in others. These feelings relate to how and if people test. Our results suggest that HIVSmart! has a role to play in providing care to testers/patients, but also show the importance of human care providers. Attending to affect, action and meaning are essential in developing HIV testing programs, including apps and other mHealth strategies, which provide good care and encourage people to test.

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CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTIONS

Ricky Janssen: Conceptualization (equal); formal analysis (lead); writing-original draft (lead); writing-review & editing (lead). **Nora Engel:** conceptualization (equal); formal analysis (equal); writing-original draft (equal); writing-review & editing (equal). **Nitika Pant Pai:** Conceptualization (equal); funding acquisition (lead); project administration (lead); supervision (lead); writing-review & editing (supporting). **Aliasgar Esmail:** Data curation (supporting); project administration (equal); resources (equal); supervision (equal). **Keertan Dheda:** Funding acquisition (lead); project administration (equal); resources (equal); supervision (equal). **Réjean Thomas:** Project administration (equal); resources (equal). **Anja Krumeich:** Conceptualization (equal); Formal analysis (equal); writing-original draft (equal); writing-review & editing (equal).

DATA AVAILABILITY STATEMENT

For privacy and confidentiality reasons, research data are not shared.

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REFERENCES

- Buse, C., Martin, D. & Nettleton, S. (2018) Conceptualising ‘materialities of care’: making visible mundane material culture in health and social care contexts. *Sociology of Health & Illness*, 40, 243–255.
- Chiou, P.Y., Chien, C.Y., Lee, A., Mark, H. & Ko, N.Y. (2019) Experiential learning of HIV self-test among student nurses: A qualitative study. *Nurse Education Today*, 79, 111–116.
- Davids, M., Dheda, K., Pant Pai, N., Cogill, D., Pai, M. & Engel, N. (2015) A survey on use of rapid tests and tuberculosis diagnostic practices by primary health care providers in South Africa: implications for the development of new point-of-care tests. *PLoS One*, 10, e0141453.
- Department of Health: Republic of South Africa (2016) *National HIV Testing Services Policy: 2016*. Retrieved June 26th, 2019 from <https://sahivsoc.org/Files/HTS%20Policy%2028%20July%20final%20copy.pdf>.
- Engel, N., Davids, M., Blankvoort, N., Dheda, K., Pant Pai, N. & Pai, M. (2017) Making HIV testing work at the point of care in South Africa: a qualitative study of diagnostic practices. *BMC Health Services Research*, 17, 408.
- Epstein, S. (1996) *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Gourlay, A., Wringe, A., Birdthistle, I., Mshana, G., Michael, D. & Urassa, M. (2014) “It Is Like That, We Didn’t Understand Each Other”: exploring the influence of patient-provider interactions on prevention of mother-to-child transmission of HIV service use in rural Tanzania. *PLoS One*, 9, e106325.
- Hennink, M., Hutter, I. & Bailey, A. (2011) Chapter 3: The design cycle. In: *Qualitative research methods*. Sage.
- Janssen, R., Engel, N., Esmail, A., Oelofse, S., Krumeich, A., Dheda, K. et al. (2020) Alone but supported: a qualitative study of an HIV self-testing app in an observational cohort study in South Africa. *AIDS and Behavior*, 24, 467–474.
- Lupton, D. (2018) ‘I Just Want It to Be Done, Done, Done!’ *Food Tracking Apps, Affects, and Agential Capacities, Multimodal Technologies and Interaction*, 2.
- Lupton, D. (2019) The thing-power of the human-app health assemblage: thinking with vital materialism. *Social Theory & Health*, 17, 125–139.
- Maslen, S. & Lupton, D. (2018) “You can explore it more online”: a qualitative study on Australian women’s use of online health and medical information. *BMC Health Services Research*, 18, 916.
- Merson, M.H., O’malley, J., Serwadda, D. & Apisuk, C. (2008) The history and challenge of HIV prevention. *The Lancet*, 372, 475–488.
- Muessig, K.E., Nekkanti, M., Bauermeister, J., Bull, S. & Hightow-Weidman, L.B. (2015) A systematic review of recent smartphone, Internet and Web 2.0 interventions to address the HIV continuum of care. *Current HIV/AIDS Reports*, 12, 173–190.
- Ondenge, K., Renju, J., Bonnington, O., Moshabela, M., Wamoyi, J., Nyamukapa, C. et al. (2017) ‘I am treated well if I adhere to my HIV medication’: putting patient-provider interactions in context through insights from qualitative research in five sub-Saharan African countries. *Sexually Transmitted Infections*, 93(Suppl 3), 1–6.
- Pai, N.P., Esmail, A., Marathe, G., Oelofse, S., Pretorius, M., Smallwood, M. et al. (2018) 1275. *Will an App-Optimized HIV Self-testing Strategy Work for South Africans? Results from a Large Cohort Study*. Open Forum Infectious Diseases, 2018. Oxford University Press US. S388–S388.
- Pant Pai, N., Smallwood, M., Desjardins, L., Goyette, A., Birkas, K.G., Vassal, A.F. et al. (2018) An unsupervised smart app-optimized HIV self-testing program in Montreal, Canada: cross-sectional study. *Journal of Medical Internet Research*, 20, e10258.
- Public Health Agency of Canada (2012) *Human Immunodeficiency Virus: HIV Screening and Testing Guide*. Retrieved June 26th, 2019 from http://publications.gc.ca/collections/collection_2013/aspc-phac/HP40-76-2012-eng.pdf.

- Ritchwood, T.D., Selin, A., Pettifor, A., Lippman, S.A., Gilmore, H., Kimaru, L. et al. (2019) HIV self-testing: South African young adults' recommendations for ease of use, test kit contents, accessibility, and supportive resources. *BMC Public Health*, 19, 123.
- Schafer, K.R., Albrecht, H., Dillingham, R., Hogg, R.S., Jaworsky, D., Kasper, K. et al. (2017) The continuum of HIV care in rural communities in the United States and Canada: what is known and future research directions. *Journal of Acquired Immune Deficiency Syndromes*, 75, 35.
- Schnall, R., Bakken, S., Rojas, M., Travers, J. & Carballo-Diequez, A. (2015) mHealth technology as a persuasive tool for treatment, care and management of persons living with HIV. *AIDS and Behavior*, 19(Suppl 2), 81–89.
- Simelela, N., Venter, W.D., Pillay, Y. & Barron, P. (2015) A political and social history of HIV in South Africa. *Current HIV/AIDS Reports*, 12, 256–261.
- Singleton, V. & Mee, S. (2017) Critical compassion: Affect, discretion and policy–care relations. *The Sociological Review*, 65, 130–149.
- Tucker, I.M. & Goodings, L. (2017) Digital atmospheres: affective practices of care in Elefriends. *Sociology of Health & Illness*, 39, 629–642.
- Van Heerden, A., Harris, D.M., Van Rooyen, H., Barnabas, R.V., Ramanathan, N., Ngcobo, N. et al. (2017) Perceived mHealth barriers and benefits for home-based HIV testing and counseling and other care: Qualitative findings from health officials, community health workers, and persons living with HIV in South Africa. *Social Science and Medicine*, 183, 97–105.
- Witzel, T.C., Gabriel, M.M., McCabe, L., Weatherburn, P., Gafos, M., Speakman, A. et al. (2019) Pilot phase of an internet-based RCT of HIVST targeting MSM and transgender people in England and Wales: advertising strategies and acceptability of the intervention. *BMC Infectious Diseases*, 19, 699.
- Wright, S. (2019) From 'holding pen' to 'a space to breathe': affective landscapes in a newly-integrated sexual health clinic. *Sociology of Health & Illness*, 41, 806–820.
- Zhao, Y., Zhu, X., Perez, A.E., Zhang, W., Shi, A., Zhang, Z. et al. (2018) MHealth approach to promote Oral HIV self-testing among men who have sex with men in China: a qualitative description. *BMC Public Health*, 18, 1146.
- Zvonareva, O. & Akrong, L. (2015) Developing clinical research relationship: Views from within. *Developing World Bioethics*, 15, 257–266.

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