Caring together with digital technology

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Caring Together with Digital Technology - English Summary

Have you ever done a self-test? What was it like? Were the results what you expected? Have you ever stopped to think about what made your self-testing experience work successfully? In **the introduction** of my thesis, I show that doing a self-test and knowing the result is not necessarily as simple as it is made out to be in policy – it relies on the support of different people, places and things. Regardless of whether it's for pregnancy, HIV, COVID-19, or something else altogether, self-testing contributes to how we understand our body and shapes what we do and how we relate to health services and the people around us. As self-tests play an increasing role in our daily lives, it is worth stopping to reflect on and explore what people do with self-tests. How or why do people interact with self-tests in particular ways, how are self-tests made to work in particular settings, and how do self-tests contribute to (good?) health care practices?

In this thesis, I use the case of oral HIV self-testing (HIVST) to explore the role of the self-test and how it is made to work in two different places (Montreal, Canada and Cape Town, South Africa). Yet, the self-test is only part of the practice I study. Digital health, which includes technologies such as smartphone applications, websites, wearable sensors and telemedicine, also plays an increasing role in healthcare practices. For instance, you may know someone who uses an app to track how many steps they take in a day, to track how many calories they ingest, or to track their menstrual cycle. These digital health technologies also play a role in how we understand our body and what we do. In my case study, I investigate how a smartphone app, called HIVSmart!, which was designed to help people do HIV self-testing alone (outside of the clinic context), plays a role in the practice of HIVST. In this thesis, I aim to answer the question: how does HIVSmart! play a role in how people do self-testing in different contexts and how does it play a role in HIV diagnosis and good HIV care? Throughout this thesis, I explore what it takes to make this app and self-test work in practice, and look at which actors (both human and non-human) are involved in this process. In order to help me investigate these questions, I develop a conceptual approach that helps explain the practice of self-testing with digital health technology.

While a team of researchers in Cape Town studies the app from a quantitative perspective (i.e. using statistical methods), in contrast, I study the app and self-testing using an ethnographic approach. This means I try to understand the practice of self-testing with the app from the perspective of those working in and participating in the study in Cape Town. My data collection methods include doing individual interviews, a focus group discussion, as well as observation and informal discussion with study participants and staff in the various clinics where people are working with the app. In addition to this, I also conduct interviews with study staff and participants in Montreal, who previously worked with an earlier (web-based) version of HIVSmart!.

In **Chapter 2**, I zoom in on the context of Cape Town, South Africa, and show how HIVSmart! supports people in the process of HIVST. However, I also show that, although the

app is designed to help people do self-testing at home, or outside of the clinic context, this is not so straightforward in practice. Some people do not have phones, while for others the app will not download on the phones they have. In addition, some people prefer to work with the app and do the HIVST at the clinic with the support of study staff, or prefer to do HIVST at the clinic because they do not have private space at home. The study design is adjusted and study staff work to make the app and self-test align to the Cape Town context. They provide tablets on which to do the app, and private spaces are made available around the clinic where people can work with the self-test and app either alone, or with the support of a nurse or healthcare worker (HCW). I show that, although the app was designed to help people do HIVST on their own outside a clinic context, people do HIVST with the app in various ways: some people do it alone, while others do it with the support of clinic staff, family or friends. Some study participants do HIVST at the clinic while others do it at home. The app provides support during HIVST and the study is carried out in a flexible way – these two aspects help participants in the study to do the app and HIVST in a way that is suited to their particular situation and needs. Therefore, in this chapter, I show that for the app and self-test technology to work, they must be aligned to a particular setting.

In **Chapter 3** I use data from both Cape Town and Montreal to consider how the app and self-test make people feel through the process of testing and what this means for how people work with the technology. To do this, I employ the concept of "affect". I also take seriously the notion that humans do not alone have agency in using a technology, but that agency (i.e. the ability to act or choose to act in a particular way) is something that is co-produced through interactions between people and technology. Therefore, I show that how people work with the app and self-test, and how a person is made to feel in the process, is not just related to what the app is designed to do. People also bring with them previous experiences of HIV testing related to the particular context – these experiences are shaped by the local histories of HIV and health services. For example, participants who have previous experiences with busy or judgmental healthcare staff appreciate being able to do HIVST with the app instead of a person. In contrast, some people, who have developed trusting relationships with their healthcare provider in communities where health services were designed to meet the needs of a particular community, do not necessarily see the additional need for an app and self-test in terms of worrying about judgement, but instead consider the convenience of this approach. At times, the limitations of the app in terms of communication or support means that the technology is not necessarily the right fit for study participants or requires further adjustment or support from study staff. This chapter therefore reveals that in studying an app and self-test, researchers and implementers need to go beyond looking at only what the app does or how a person uses the technology separately. They must also consider how a person, the app, the self-test, and a person's previous experiences, come together to contribute to how a person works with the app and self-test, how this makes people feel and how this in turn contributes to what actions a person takes following their experience with HIVST.

Chapter 4 focuses on how people come to understand or know their HIV status through working with the app and self-test. I show that knowing one's HIV status is not only about correctly doing and interpreting the self-test. Rather, I use examples from my fieldwork to illustrate how participants in Cape Town draw on knowledge of testing routines, symptoms, results of other testing methods, the interpretation of healthcare providers, and personal risk behaviors when interpreting the result of their self-test. In some moments, aspects of the app and self-test, such as the video instructions, visual cues in the app, similarities between the self-test and other kinds of testing, the novelty of the oral self-test, previous test results, and "good" behavior, contribute to people's knowledge or certainty around their HIVST result. In other moments, uncertainty around the self-test result arises due to doubts about the "new" self-test and its reliability, stress while doing the self-test, or due to contradictions between "risky" behaviors and the results provided by the test. In these moments, participants turn to other people and things that make up the "assemblage" of HIV testing in the Cape Town setting, such as additional testing methods or healthcare staff. The different things that people take into consideration through the self-testing process, such as symptoms, risky behaviors, abiding by guidelines for testing, or the testing method itself, change between test experiences. HIV self-testing and test interpretation are an iterative process. This chapter also illustrates the collaborative nature of self-testing, as study participants actively draw on the people and things that make up HIV testing in their particular context, to understand their HIV self-test result together with the app.

In **Chapter 5,** I use my empirical material to reflect on the challenges that arise when implementing digital health technology. I explore how these challenges, and the work done by study staff to help technology align to a particular setting, become lost in current evaluation approaches. Using the WHO's 2016 document entitled "Monitoring and evaluating digital health interventions: A practical guide to conducting research and assessment", I contrast the simplicity of monitoring and evaluation measures with the daily complexities illustrated by research staff in their efforts to make the app and self-test work in Cape Town and Montreal. In this chapter, my analysis shows how the app, and each setting in which it works, changes over the course of the research study. I also reveal how the app is "easy to use" and "useful", not just because of its design or function, but also because of the effort of study staff who help the app to become easy and useful over time. By reflecting on my empirical material and the ways in which the study staff help the app align and work, I propose different kinds of questions that researchers should ask throughout monitoring and evaluation of digital health technology. These questions focus on capturing the novel practices created throughout the research process in the hopes of translating and taking up these practices when implementing the technology beyond the study setting. This chapter reveals the changing nature of technology throughout the research process and the collaboration necessary to make a technology work.

In the **discussion and conclusion** of my thesis, I reflect on the implications of my findings for how we understand the practice of self-testing, the role of digital health technology,

and the implementation and evaluation of digital health technology. I show how the conceptual approach I develop through my thesis has the potential to improve the design, implementation and evaluation of digital health technology and diagnostic services. I argue that to better understand how technology plays a role in providing good care to people, we need to focus on how a technology is adapted and aligned to work within a specific context. This takes time and effort by the people working with digital health technology and requires human and physical resources. In addition, we cannot only focus on what an app is designed to do, but how a person and app come together to create opportunities for action – this interaction also generates feelings, which in turn contribute to what a person does with the technology. What a person does with an app and self-test is therefore shaped by their personal history of HIV testing, as well as local histories around HIV and the development and provision of health services. Furthermore, researchers and implementers who focus on digital health and self-testing need to find ways of capturing how people and things collaborate to make the technology work, while also considering how the technology and role it plays change over time. Finally, I argue that the questions I raise using my conceptual approach go beyond digital health and self-testing, and can be used to help improve the way we implement, monitor and evaluate other kinds of health technology, such as vaccines, all with a focus on how to provide good care.