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The ethics of mHealth: Moving forward

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ABSTRACT

There is great power and promise for mobile health (mHealth) technology in the realms of clinical practice and research. By offering the opportunity to reshape the interaction between clinician and patient or researcher and subject, the introduction of this technology allows clinicians and researchers access to larger quantities of more timely and reliable data. The potential developments are significant, and they are ethically relevant. With all technological developments, however, come new sets of ethical risks. In this paper, I assess the ethics of mHealth. I argue that while we have an ethical obligation to advance this work in order to further the quality and scope of care, the use of mHealth technology also presents challenges that must be addressed before and during the use of this technology. After describing the ethical landscape, I offer a pragmatic approach to meeting some of these challenges and minimizing ethical risk by switching from a privacy-centered frame to a consent-centered frame.

1. Introduction

According to Pew Research Center, almost two thirds of American adults now own a smartphone [1], and as mobile technology becomes more affordable and accessible, that number is only expected to grow. The ubiquity of mobile technology, and the integration of mobile devices into many facets of our lives, has given rise to an explosion of health-related applications. In 2015, the percentage of smartphone users who downloaded a fitness app onto their phones was over 58%, even though those early applications were often frustrating or unsatisfying to use [2]. Companies like Fitbit, Garmin, and Misfit, makers of wearable fitness trackers, offer options that sync with smartphones or serve as stand-alone devices, and the market for their technology is thriving. Fitbit alone has sold more than 38 million devices since 2010 [3]. The success of this technology suggests that mHealth may prove to be an unobtrusive, low-barrier method to make advances in both clinical and research settings, benefitting all involved parties.

1.1. Promise and potential

For clinicians and researchers alike, mHealth technologies offer unpresented opportunities. Collecting passive data from patients and subjects allows for a fuller and more nuanced picture of the data in context. A clinician monitoring a diabetic patient might rely on a glycated hemoglobin test, the current gold standard test that gives information on how well the patient's blood glucose is controlled. The glycated hemoglobin test is not ideal in many respects — the average lifespan of a red blood cell means that the test can only give us a general idea of glucose control over the past 180 days (and no longer), and the test may be misleading for patients with iron deficiency or certain genetic variants [4]. The test also requires an in-person lab visit and a blood sample, factors that are both non-negligible in financial cost and inconvenient for the patient.

Developments in mHealth may dramatically change this picture. Researchers are hopeful that the use of mHealth technology and the advancement of commercially viable wearable and/or implantable sensors will soon revolutionize this whole process [5].

Should mHealth technology be used in this context, the clinician would have access to a very different kind of dataset. Instead of using a time-limited and potentially inaccurate lab result, the clinician would have access to an enormous amount of situationally-relevant information. She would be able to discern nuances in data, such as whether the patient was experiencing any dangerously low levels of blood glucose, or whether there were non-trivial episodes of postprandial spikes. All of this information gets lost in the brute aggregate of a glycated hemoglobin test.

Glycated hemoglobin tests became a gold standard, however, in direct response to another challenge. Diabetics are, of course, able to maintain their own logs of blood glucose values at home, and then report them to clinicians or researchers. In theory, those logs could capture some of the rich data lost in a glycated hemoglobin test. In practice, that is often not the case. Clinicians and researchers have long known that self-reported data is highly prone to inaccuracies. When researchers have tested the accuracy of patient-reporting of health-

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related claims, a strong trend emerged. Whether through lapses in memory, shame-based information withholding, or intentional deception, patients and subjects are often unreliable narrators of their own behavior. Whether the self-reporting concerns behavior such as drug use [6], smoking [7], compliance in medication use [8], or flossing one's teeth [9], relying on patient report often yields inaccurate results. The consequences of this gap in reliability can be significant. Formulating maximally effective treatment plans requires understanding how patient behavior may be contributing to the situation at hand, and inaccurate data can lead to expensive or unnecessary interventions. In research contexts, inaccuracy in data collection requires lower confidence in the conclusions of studies, often requiring much larger sample sizes to compensate for patient errors and omissions.

The use of mHealth technology can alleviate these problems by removing the patient or subject from the role of narrator. Not only is sensor-gathered data incapable of omission or deception, it is also capable of collecting much richer data sets. It would be an enormous burden on patients to collect and report their blood glucose every five minutes, for example, but a wearable blood glucose monitor can provide such frequent data collection in an unobtrusive way, freeing patients from making extra visits to a clinic or lab and letting them just go about their days. This leads to both more data and better data.

mHealth technologies also allow a more patient-centered experience. Fitness trackers and apps, for example, place patients in the role of co-investigators, watching as their step counts grow or blood pressure lowers. A union between smartphones and healthcare means that patients can use mHealth technology not merely to monitor their health, but to improve it. Sometimes this might look like using mHealth to increase self-management skills and become more active partners in healthcare [10]. Other times, it might look like clinicians and researchers using mHealth technology to send "just in time" reminders and text messages to patients, improving compliance with behavior like medication adherence [11] or oral hygiene [12].

When we speak about the potential and promise of mHealth, it is easy to imagine that these benefits are strictly pragmatic, as if they stand on one side of a ledger, waiting to be balanced against a list of ethical risks. This approach is a mistake. When we speak of the ethical landscape of mHealth, the potential of this technology to increase quality of care and lower patient burden is indeed part of the story we must tell if we aim to do ethics properly. In fact, the potential of this technology, in many respects, grounds an ethical obligation to pursue mHealth, and to pursue it well. In the language of Principlism, beneficence is the obligation of health institutions to "do good," that is, to provide benefit to patients and subjects (and to society at large) to the highest degree that is possible [13]. In the language of normative ethics, we can understand this obligation in terms of the special relationship between clinicians and patients, or researchers and subjects. Clinicians and researchers hold disproportionate power over their patients or subjects. There is asymmetry in skill, knowledge, and relational cost. Built into this relational power inequality is an extra obligation to provide benefit to the disadvantaged member of the relation. This obligation serves as a check against exploitation of the patient's (or subject's) vulnerability. Thus, if the use of mHealth technology allows us to provide better care, then this is a foundational reason why we have an ethical obligation to pursue the development of this technology, but with the protection of the user at the forefront.

Our ethical obligation to pursue this technology is made most clear by the following potential benefit: mHealth allows us to deliver care and services to the most vulnerable and underserved populations. Research is underway to use this technology to serve resource-poor populations [14] around the globe [15], where smartphone use is growing more and more common [16]. With increased saturation of mobile devices, clinicians and researchers can work on conquering shortages of care providers and last mile health care challenges. This technology has the potential to revolutionize global health care, but it can also help vulnerable populations in rich nations. The potential for mHealth technology to accurately capture the state of health of vulnerable populations, and to take concrete measures to increase health outcomes, is significant. The ability to use a platform that people have already integrated into their lives lowers the burden of accessing healthcare. This is especially important for populations like the homeless [17] or people fighting addiction [18], where there are high social, financial, and structural costs to seeking care.

The ability to access and serve traditionally underserved populations is perhaps the most unique ethically relevent feature of this technology. Both medical ethics and research ethics appeal to the principle of justice − the idea that it is important to accurately distribute the benefits and risks of research and healthcare [13,19]. The notion of "accuracy" here ideally captures a state of affairs where we recognize our unique obligations to the most vulnerable in society. This involves orienting our priorities in ethically required ways and constructing our choices to make sure we center the populations who are most struggling, especially those who are struggling due to structural and institutional inequalities. The use of mHealth technology allows us to meet this obligation in a way that hasn't previously been possible.

All of that said, the features that make mHealth so promising − the evolution of the clinician/patient relationship, the collection of highly accurate passive data, the serving of vulnerable and underserved populations − raise unique ethical risks as well. In the next section of this paper, I will consider a few of these challenges.

1.2. The challenges

The unique features of mHealth technologies revolve around data, both in the methods through which data is obtained and in the quality and quantity of what is collected. Whenever benefits come from large and novel datasets, there are inevitably questions about the ethical risks attached to those benefits. In this paper, I will discuss four of these challenges, and while this list is in no way exhaustive, it does capture some of the more daunting ethical obstacles that must be overcome.

2. Patient access

One of the benefits of mHealth is that it can provide an opportunity for patients and subjects to become more active partners in their own health. Considering the benefits of prohealth behaviors and lifestyle choices, this is certainly an attractive feature. This benefit, however, depends on one condition being met: patients and subjects having access to their own data.

This condition raises a difficult ethical question. In traditional care delivery models, patients are not routinely given access to their raw data for important reasons. Asking a patient to make sense of an uninterpreted x-ray or raw lab result, for example, is to invite opportunities for confusion and potential distress. Part of the content of clinical training is the skill of interpreting these data and communicating the results in layperson's terms. This skill takes significant time and education to develop.

Thus, there is a risk to allowing patients access to raw data. Without training and experience interpreting data, patients often turn to internet search engines and anecdotal evidence, at times requesting or demanding treatment from clinicians that sounds attractive but goes against the best current models of practice [20]. Patients might also take matters into their own hands, adjusting treatment plans without the advice or participation of healthcare teams. At minimum, exposure to uninterpreted data might cause the patient to experience unnecessary levels of anxiety or concern.

This phenomenon has already come to pass with one of the earliest uses of "mHealth" technology: continuous positive airway pressure (CPAP) machines used for the treatment of sleep apnea. When patients are evaluated for sleep apnea, testing involves at least one night as part of a formal sleep study, where the patient is connected to leads and sleep quality and oxygen saturation are monitored by formally trained