Dependence on Digital Medicine in Resource-Limited Settings

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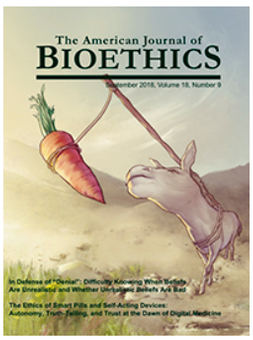

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Dependence on Digital Medicine in Resource-Limited Settings

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With technology permeating nearly every aspect of daily life, it is no surprise that digital medicine is taking on an increasingly important role in medical care. In their sweeping analysis of ethical considerations arising from use of digital medicine, Klugman and colleagues (2018) make a brief mention of dependence upon digital medical devices as one such consideration.

One type of widely used digital medical technology is electronic adherence monitors (EAMs), which have been used worldwide to measure adherence to medications and behaviors ranging from inhaled albuterol to scoliosis braces. Over the past decade, we have used increasingly sophisticated EAMs to measure and attempt to improve antiretroviral therapy adherence among people living with HIV in sub-Saharan Africa, and we have conducted qualitative research on EAM users' experiences in Uganda. In a series of qualitative studies with EAM users in Uganda, some interviewees have described becoming dependent upon EAMs to take antiretroviral therapy, an unintended consequence of using the device for months to years (Campbell et al. 2016, Musiimenta 2018).

Dependence upon digital medical technology—which we define as physical or psychological reliance upon a technology to maintain health—may prove risky for different reasons. For instance, Klugman and colleagues highlight the risks to health and potential loss of trust in digital medicine that may occur if patients become dependent upon digital medical technology that then experiences a glitch and stops functioning. Indeed, we have all had to reboot our cellphones at inopportune times; imagine if our phones were wired to control our pacemakers or insulin pumps. But this commentary characterizes another form of dependence on medical technology.

INTRINSIC AND EXTRINSIC MOTIVATION

Becoming dependent upon a medical device, particularly one that monitors and prompts interventions to change behavior (e.g., a wireless EAM or the direct ingestion monitors that Klugman and colleagues cite) may also result in decreased self-reliance, and increased reliance upon the device and on its attendant support structures (Bowes, Dawson, and Bell 2012, Mittelstadt et al. 2014, Percival and Hanson 2006). EAM users we interviewed typically described motivation to adhere to antiretroviral therapy as arising from a mix of what Ryan and Deci call "intrinsic" factors (e.g., a personal desire to be healthy) and "extrinsic" factors (e.g., desire to demonstrate socially desirable adherence to the researchers monitoring one's adherence) (Ryan and Deci 2000). Our own view is that reliance upon extrinsic motivating factors to adhere to a health behavior is not in itself ethically problematic. EAM users' adherence may have depended upon the devices and the pressure to adhere arising from knowledge that their adherence was being watched. This scenario does not represent a flaw in and of itself: it is hardly different from dependence upon any number of other tools that patients use to achieve desired health behavior, from pill organizers to seeking out adherence supporters in their communities (Haberer, Musinguzi, and Tsai 2017). Importantly, most of our interviewees were happy to forfeit a degree of control over their adherence in order to achieve better adherence (Campbell et al. 2018).

However, when extrinsic factors "crowd out" intrinsic factors or the intrinsic factors are simply absent, harm may arise if these extrinsic factors become unavailable. Patients who receive extrinsic motivation from digital health devices may be left worse off if their device fails without possibility of repair, becomes incompatible with other necessary digital health supports or local technological infrastructure, or is removed. For example, patients who become dependent upon a digital adherence device to take their medications may become less adherent, and hence more ill, when the device is repossessed, a concern that some of our interviewees raised. When asked what would happen if the EAM were retrieved at the end of one study, one EAM user said:

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> Yes it will disturb me [to have the device removed] because I have been used to it and I think I might even miss my [antiretroviral] doses if I do not have it … it has been reminding me.

Another stated:

> Surely if they take [the EAM] away I can be disturbed. Of course I know they can take it if they want and I can still take my drugs, but surely it can be difficult for me because I will not have a device to motivate me to take my drugs.

OPTIMAL FUNCTIONALITY VERSUS ACCESS AND COMPATIBILITY

These quotes raise a key distinction in the risks arising from digital health technology dependence. On the one hand, Klugman and colleagues highlight risks that may arise if patients rely upon a digital medical technology that in itself is not optimally functional or "dependable." For instance, a patient may be harmed if her continuous glucose monitor inadvertently malfunctions and provides inaccurate and/or inadequate data for insulin dose adjustment.

On the other hand, our interviewees described a scenario in which a functioning digital health technology that they depend upon—the EAM—may no longer be available to them. Continued access to digital technology relies upon a network of structural components, such as the long-term compatibility of a device with a cellular network or clinician's computer, and ongoing funding from institutions that supply or support the device.

If intrinsic motivation has been crowded out by dependence upon digital health technology, risks arising from suboptimal functioning of that technology can often be addressed through simple technical fixes (e.g., replacing a device's battery). Loss of access or compatibility arguably proves harder to mitigate: cohorts of device users may be at risk if a brand of device is no longer supported on a local cellular network, and there may be little recourse when, say, a longitudinal study ends and must recall devices upon which users are dependent without a ready replacement.

SCALABILITY AND SUSTAINABILITY: DEPENDENCE UPON DIGITAL MEDICINE IN RESOURCE-LIMITED SETTINGS

Klugman and colleagues discuss dependence upon digital medical technologies like pill ingestion monitors and continuous glucose monitors that are poised to expand in developed health systems. In contrast, the dependence-related challenges arising from lack of access to or compatibility of digital medical technologies may be particularly pronounced in resource-limited settings. Sub-Saharan Africa, for instance, is expected to have more than 500 million unique cellphone subscribers by 2020 (GSMAssociation 2017), and governmental and nongovernmental health organizations increasingly capitalize on growing digital connectivity to promote health behaviors in some of the world's most impoverished communities.

Unfortunately, despite promising pilot studies of digital health interventions for many of the most pressing challenges in global health, digital technologies, typically employing cellphones ("mHealth"), have been notoriously difficult to scale (Tomlinson et al. 2013). Moreover, the national, international, and nongovernmental health organizations that support digital health tools in resource-limited settings are themselves often only transiently engaged and incompletely coordinated with health care providers in these settings. This lack of coordination creates further barriers to sustainability and effective integration of novel digital health tools into patients' medical care. Therefore, patients in resource-limited settings who have become dependent upon digital medical technologies often face the abrupt removal of these technologies.

To date, no formal guidance exists to assist the myriad health ministries, researchers, and aid organizations that use digital technologies in resource-limited settings, frequently leaving each to navigate solo the complex and ethically uncomfortable process of closing digital medicine-based programs. Future ethics guidelines on use of digital technology in resource-limited settings should provide direction on how to ensure that patients or research subjects will not be harmed by loss of technologies upon which they have become dependent. Some health organizations have begun to systematically address issues arising from new digital health technologies in resource-limited settings—the Ugandan Ministry of Health, for example, is organizing a committee of "digital stakeholders" (including United Nations agencies, corporations, and academic institutions) to coordinate introduction of health technology ventures in Uganda. Such forums could provide venues to create coordinated national or regional strategies addressing ethical challenges like dependence that arise with the growth of digital medicine in resource-limited settings.

KNOWLEDGE GAPS

How should clinicians and researchers respond to their patients' and study participants' dependence upon sustained access to digital technology, and to the potential risks associated with removing technology that users have become dependent upon? How should users' expectations about sustainability of technologies be managed? How should technologies be removed when studies conclude or funding for sustained use of a digital health technology dries up? A first step toward answering these questions is to map who is most likely to become dependent upon the technology, the magnitude of dependence that users develop, and the long-term physical and psychological consequences of losing access to digital medical technology. The depth of dependence and potential risks associated with subsequently removing the technology will often vary

substantially due to technology-related, patient-related, and provider-related factors. However, research on digital technologies typically ceases when devices are removed at the end of a study, leaving clinicians with little sense for the long-term effects of dependence upon technology that is withdrawn.

Qualitative research from members of our team has shown that while a subset of patients enrolled in monitoring studies may feel harmed when EAMs are withdrawn at the end of a study, other patients feel no such effect and rather appear to acquire intrinsic motivation for adherence. Those who relied on the extrinsic motivation arising from EAMs reported stress, lack of psychological support, and social isolation, all of which exacerbated lack of resiliency to device removal (Musiimenta 2018). Conducting further research on health behaviors and psychological well-being after digital health technology is removed would significantly aid in addressing dependence.

STEPS FORWARD

Challenges with becoming dependent upon digital health extend beyond Klugman and colleagues' concerns about technology malfunction. Patients who rely upon digital health face potential harm when the technology is no longer available to them. This may prove particularly risky for patients in resource-limited settings where sustained access to functional digital medical technology is far from guaranteed. Further research is needed to investigate dependence that may arise with long-term device use. Moreover, not all patients become dependent upon digital health technologies, and further research is needed to understand the factors that may predispose patients to dependence. Ultimately, providers have an ethical obligation to optimize their patients' health; they should remain vigilant against technology that ultimately does more ill than good.

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