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Surveillance and Digital Health

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The ethical challenges posed by digital medicine and the potential impact on the therapeutic alliance are considerable. With specific applications of digital medicine, such as "smart pills," it is critical to consider whether the digital medicine approach offers sufficient potential benefit to offset the potential risks. While a smart pill might be more effective than other current methods at establishing whether a patient is taking a medication, the power imbalance implied by digital surveillance and whether its implementation would be compelled (or pressured) by third-party payers need to be studied, particularly before erosions to patients' autonomy begin to occur. These concerns are of particular importance when the primary benefits of this technology appear to be financial gains for health care companies, rather than significant health gains for individuals and society.

Medication nonadherence, the issue that the digital medicine "smart pills" described by Klugman and colleagues (2018) are meant to address, is a significant problem. Being able to tell when patients are taking their medication is a component of studying and addressing medication nonadherence. Yet one must weigh the proposed benefits of tracking people's pill consumption against the impact such patient surveillance can have on the therapeutic alliance. A useful comparison for a surveillance approach to medication nonadherence comes from the ethics literature on directly observed therapy (DOT). DOT violates an individual's privacy and autonomy so that the health care system can "directly observe" compliance with a directed medication, usually in the context of an infectious disease that poses a clear threat to public health (Sagbakken et al. 2013). Multidrug-resistant tuberculosis is a classic example where the World Health Organization regularly utilizes DOT (Karumbi and Garner 2015; McDermott et al. 2018). DOT implies distrust between provider and patient, or at least apathy to the patient's agency in pursuing his or her own health. The power imbalance between the medication provider and the patient is profound. Studies of treatment outcomes of DOT used in different contexts have yielded mixed results (Kronish and Moise 2017). The uncomfortable transgressions by the health care system on an individual in DOT are justified by the need to protect the larger public.

Unlike DOT, the potential benefits offered by smart pills are financial and not primarily benefits to the health of the public. The infringement on an individual's autonomy is not clearly justified. Smart pills could greatly help cost containment for profit-generating

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industries like health insurance providers, which could penalize documentable medication nonadherence. In addition to insurance profits, hospitals could easily improve re-admission rates (and avoid costly Centers for Medicare and Medicaid-imposed re-admission penalties) through improving patients' adherence to medications recommended at discharge. Monetization is the motivation behind private industry development and investment in digital health and a stronger driver of "smart pill" technology than an altruistic interest in patient health.

The primary reasons for medication nonadherence are concern regarding side effects, cost, forgetfulness, problems with drug interactions, complexity of medication management, not perceiving therapeutic efficacy, and conflicting or inaccurate patient norms or beliefs regarding medication (Marcum, Sevick, and Handler 2013). All of these psychosocial considerations are best addressed by a strong and trusting therapeutic alliance between clinician and patient, a trust made more difficult by surveillance. The more marginalized patients, at greater risk for poorer health outcomes, are the most likely to flee from increased scrutiny and a distrusting clinical relationship (Musa et al. 2009). The American Medical Association has emphasized that building trust between physician and patient is at the core of improving medication adherence (Piette et al. 2005). There needs to be particular caution when considering approaches that could easily undermine trust, such as ingestible sensors and patient surveillance. For certain subsets of patients, the idea that the doctor-patient relationship will involve constant monitoring with invasive sensors is more likely to increase suspicion and distrust. Consistently, studies have found that the most effective efforts for improving medication adherence are multicomponent and oriented toward behavioral interventions (Kronish and Moise 2017). Digital technology that presents less risk to privacy and the therapeutic relationship should be prioritized, such as medication nonadherence apps that educate patients on medication management or side effects. There are also less intrusive ways to identify nonadherence, such as monitoring pharmaceutical refills. The best benefits to the patient stem from building a strong therapeutic alliance with his or her provider. Unfortunately, a therapeutic alliance is harder to monetize. In health care, financial goals and health outcomes are not always aligned.

Ethical concerns arising from the data collection involved in digital medicine are also significant. Someone will need to watch over and interpret the ongoing collection of digital medicine data, such as whether a patient is taking his or her medicine. Who will that be? The digital medicine model seems to rely upon an idealized notion of a benevolent scientist who will interpret the data for a patient's benefit. Unfortunately, these are not idealized times. Health care providers already operate under time constraints and are unlikely to have their time protected to look at reams of adherence data. More likely, the private companies developing the digital medicine approaches would also be responsible for data collection and interpretation. Recent big-tech scandals, such as Facebook/ Cambridge Analytica, and press interviews with purveyors of privatized digital health suggest that privatized digital information collection has a profit model focused on monetizing data possession and interpretation, particularly to target third-party products and services, not unlike current social media profit approaches (Amira 2018). Leveraging patient information for profit is not the foundation for a solid, long-term health care relationship.

Digital health technology should be used in ways that enhance the physician-patient relationship (Torous and Roberts 2017). The challenges posed to the physician-patient relationship by digital medicine solutions that involve surveillance approaches must not be underestimated. While digital health approaches are often presented as gateways to utopian futures, they can also lead us to dystopian ones. Smart pills have the potential to alienate patients from care and make patients more vulnerable to private industry exploitation. Careful ethics scholarship will need to include consideration of the types of oversight, guidance, and regulation that digital medicine approaches will require in order to prevent potential abuses. Taking the time now to address the direction of digital medicine will help ensure that the physician–patient relationship does not come to resemble Big Brother.

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