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Smart Pills for Psychosis: The Tricky Ethical Challenges of Digital Medicine for Serious Mental Illness

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Craig Klugman and colleagues (2018) offer a cogent and much-needed engagement with the bioethical dimensions of new and emerging smart pill technologies. They address the possibilities of these devices in improving patient safety and health outcomes, as well as the consequences arising from their novelty and rapid development. Its merits notwithstanding, their article misses a larger ethical point about “digital medicine”—namely, how all of it is underpinned by a singular and inflexible set of values: the belief that quantitative data can provide a coherent model of the world, and the efficacy of biodata to provide us with ways of acting in it.

When we acknowledge the unique constraints and challenges posed by smart pills in the context of serious mental illness, an additional set of ethical concerns arises. The first smart pill approved is Abilify MyCite, an antipsychotic medication used in the treatment of schizophrenia, bipolar disorder, and depression. It combines aripiprazole with a digital sensor that, once in the stomach, communicates with a patch, worn by the patient, that automatically logs the date, time, and dosage of the medication. The scale of digital medicine tracking technology matched by its apparent ideological impartiality is deeply concerning in the way it ushers in profound change at the levels of epistemology and ethics. In this commentary, I briefly consider two of these concerns in the context of treatment adherence: the possibility that smart pills diminish trust in the doctor–patient relationship, and the possibility that smart pills can undermine the foundations of personal autonomy.

THE CONCEPT AND MEASUREMENT OF ADHERENCE

Adherence is a consequential problem in schizophrenia. While estimates vary by study, it is believed that about half of patients diagnosed become nonadherent to treatment, a rate largely similar to other chronic diseases (Phan 2016). Adherence is a contested concept insofar as it is imbued with meanings that extend beyond its strict definition. Klugman and colleagues define adherence as “the degree to which a patient follows medical advice, most commonly with regard to taking medications” (Klugman et al. 2018, 38).

While reliably identifying adherence remains a challenge, smart pills are thought to be promising in their novel ability to provide “direct evidence” of medication ingestion. Klugman and colleagues suggest that biodata is a better source of information compared to unreliable patient testimony. The idea that biodata and numbers speak for themselves glides over the reality that any claims to accuracy resist generalizability beyond their immediate context. The primary ethical issue raised by smart pills is how statistical information is valued relative to experiential knowledge. In accordance with Robyn Bluhm (2007), “Actual medical practice requires a fundamentally different kind of knowledge than that which is generated in quantitative studies via randomized clinical trials which are not designed to inform clinical practice” (151). Information gleaned from stringently controlled and tidy population-based studies is not easily transferable or translatable to the multiplicity and messiness of every day medical practice. Different adherences exist in different locations and practices, some of which are easily taken up and assimilated into the body of knowledge concerning schizophrenia, and some of which are sidelined, marginalized, or erased altogether (Berkhout 2017). When people become flattened categories, it injures their autonomy.

In medical practice, the experience of schizophrenia, as told by the individual living under the diagnosis, is drowned out by the voices of outside experts (physicians, clinicians, scientists, researchers), who are acknowledged as more reliable, authentic, and trustworthy in their capacity as knowers. Patients are simultaneously locked into and out of the practices that involve and affect them most directly, based on a prevailing clinical stereotype that undermines their capacity to provide truthful and reliable accounts of their own lives. This is epistemic injustice (Fricker 2007). Kristie Dotson (2011) identifies two forms of epistemic injustice that are relevant to patients with schizophrenia. These include “testimonial quieting,” which happens when a speaker from a marginalized group is not seen as a “knower,” which results in the subsequent dismissal of their testimony by the dominant group; and “testimonial smothering,” which happens when a

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speaker believes his or her testimony will be misinterpreted so the speaker self-silences. In this insidious way, people with schizophrenia, such as myself, are monolithically silenced and rendered noncredible by virtue of our diagnosis. These same moral judgments toward patients enter into the authors' analysis in concerning ways.

Following medical advice is widely understood as a form of rational action (Conrad 1985). Adherence, as a concept, is developed from the physician's perspective and viewed through a utilitarian lens, stripped of its cultural and symbolic meanings. Any refusal, protest, or partial adherence is viewed as an irrational or deviant act, a double whammy for a population of patients already considered as such. A substantial body of schizophrenia adherence literature embraces the model. This provides, for all intents and purposes, "conventional" views of adherence.

In reality, adherence is much more than taking a pill every day. An ability or desire to adhere to a medication regimen also means cultivating adequate levels of social and financial support, robust and honest communication with clinician, and sound health care beliefs. This is a crucial point. Adherence is a multifaceted cacophony, including defiance, lack of insight, substance abuse, side effects, forgetfulness, stigma, cultural influences, fragmentation of care, socioeconomic status, complexity of regimen, breakdowns in the therapeutic alliance, and trauma related to prior psychiatric care (Conrad 1985; Phan 2016; Saks 2017; Tessier et al. 2017). Despite this, many people seem to find it easier to think people with schizophrenia are, in part, responsible for their nonadherence than to acknowledge the situational factors.

And when you do not fully understand a person's context—what it feels like to be that person every day, all the small annoyances and major traumas that define that person's life—it is easy to impose abstract, rigid expectations on a person's behavior: *All people with schizophrenia should take their medication as directed. Never mind that most of them are experiencing intolerable side effects and are just fighting to feel human. Never mind that they are unable to get a good night's rest or a nourishing meal for weeks or months on end. Never mind that even in my comfortable life, easy life, I cannot go more than a month without stopping my meds for a few days or longer. They have to do better.*

Misunderstandings of mental illness have guided much of the dark history surrounding treatment of individuals with abnormal behavior—all to the detriment of patient autonomy and trust in the therapeutic alliance. By normalizing suspicion, smart pills technology reifies mistrust and discrimination by sending out a message to patients of "I don't believe you." Even Klugman and colleagues seem to imply as much, stating that "some may prefer to be able to deceive their clinicians, and this technology threatens their ability to do so" (Klugman et al. 2018, 38). The authors also articulate an understand autonomy as informed choice by suggesting that "maximally empowering patient autonomy would mean giving patients an absolute right to provide or refuse to

consent for their data to be used in research" (Klugman et al. 2018, 38).

In truth, current psychiatric practice falls short of empowering patients. As a person who lives with schizophrenia and knows intimately the radical and visceral powerlessness that comes from the experience of involuntary incarceration amid clinicians who knew me only as illness in human form, I am passionate about protecting patient rights at all costs. By autonomy, I mean the power to decide, if at all, to take medication as directed. This requires a conception of autonomy as lived within medical practice. Legal scholar and mental health policy advocate Elyn Saks (2017) argues that adherence pivots on providing patients with options to refuse treatment. Giving a patient this option provides them with active and more collaborative negotiating power in the doctor–patient relationship. The key takeaway here is that medication regimens require active support if they are going to be sustained.

SMART PILLS IN CONTEXT

The push toward privatization frames health care in technocratic and capitalist terms, increasingly through the rhetorics of democratization and patient empowerment via more conveniences and choices. The taken-for-granted narrative is that anything we can do to give patients more control and access to information to manage their health is a step in the right direction. Thus, we talk of making things "smarter" and "easier" by adding a technical dimension. These rhetorical tics allow us to bypass the larger issue of access to adequate, humane, and sensitive mental health care, which can be a daunting, if not foreclosed, process.

CONCLUSION

By framing smart pills as promising solutions to the problem of adherence, the authors rely on objective and normative assumptions and narrowly defined principles and concepts that give way to a thinking about a complex problem in a way that assumes people with schizophrenia are data points and can be aggregated. The idea that biodata and numbers speak for themselves glides over the reality that any claims to accuracy resist generalizability beyond their immediate context. In the end, the message is both simple and simplistic: Underneath it all, our concerns are all the same.

Adherence in schizophrenia is complex work. And it is that complexity that makes it tricky. We want to give patients treatments that are relevant to their illness and needs, but what they need and what we know vary widely. As bioethicists we must be mindful of technical solutions that are framed as "smart" or "easy" as these rhetorical tics allow us to bypass much larger issues in need of comparable ethical scrutiny. In this context, biodata is seen as more authentic and trustworthy than patient testimony. Physicians are rebranded as providers

who are also experts, while patients are suddenly “empowered” but also unreliable and deceitful. ■

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REFERENCES

- Berkhout, S. 2017. Enacting adherence to HIV/AIDS care: How multiplicity in medicine becomes singular story,” In *Knowing and acting in medicine*, ed. R. Bluhm, 203–220. London: Rowman & Littlefield International.
- Bluhm, R. 2007. Clinical trials as nomological machines: Implications for evidence-based medicine. In eds., Kincaid, H., J. McKittrick, *Establishing medical reality: Essays in the metaphysics and epistemology of biomedical science*, 149–166. Dordrecht: Springer.
- Conrad, P. 1985. The meaning of medications: Another look at compliance. *Social Science & Medicine* (1982) 20(1): 29–37.
- Dotson, K. 2011. Tracking epistemic violence, tracking practices of silencing. *Hypatia* 26(2): 236–57.
- Fricker, M. 2007. *Epistemic injustice: Power & the ethics of knowing*. New York: Oxford University Press.
- Klugman, C. M., L. B. Dunn, J. Schwartz, and I. G. Cohen. 2018. The ethics of smart pills and self-acting devices: Autonomy, truth-telling, and trust at the dawn of digital medicine. *American Journal of Bioethics* 18(9): 38–47.
- Phan, S. V. 2016. Medication adherence in patients with schizophrenia. *The International Journal of Psychiatry in Medicine* 51 (2): 211–9.
- Saks, E. 2017. The Consent Dilemma. *Politico*, August 9, <https://www.politico.com/agenda/story/2017/08/09/drug-treatment-mental-illness-000491>
- Tessier, A., L. Boyer, M. Husky, F. Baylé, P.-M. Llorca, and D. Misdrachi. 2017. Medication adherence in schizophrenia: The role of insight, therapeutic alliance and perceived trauma associated with psychiatric care. *Psychiatry Research* 257: 315–21.

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). Multi-drug-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 industries like health insurance providers, which could penalize documentable medication nonadherence. In addition to insurance profits, hospitals could easily improve re-

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