

Invited Editorial

Samantha Adams Festschrift: Keeping Close Tabs—In Memoriam Samantha Adams

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Appl Clin Inform 2018;9:503–506.

Introduction

I had the opportunity to share a platform with Sam Adams twice, once at an American Medical Informatics Association panel and also once in London, at the European Centre for Ethics, Law and Governance in Health Information Technology. In 2014, we had agreed to speak on aspects of the “commodification” of patient information. In the abstract for my contribution I had written:

Much of the discussion of “commodification” of patient—and more generally, personal—data revolves around the use that those who gather data on a large scale make of this wealth of information, or more precisely, about the ways they turn data, often of uneven quality but in large volumes, into information with intrinsic value. [...]

In healthcare, analytics has been applied to service improvement in hospitals and other provider organizations. The large-scale distributed research data repositories currently envisioned by such projects as the PCORI Clinical Data Research Networks, are expected to bring value to healthcare delivery through comparative effectiveness research (CER) and patient-reported outcomes. In due course, it is anticipated that industry, including pharma, will be able to mine these to identify optimal care pathways, to accelerate drug development, to rationalize services, and to manage public health.

A more intimate example lies in the concept of Microsoft's HealthVault, which, at least at one time, had ambitions to join up all the commonly collected health-related information about a person (under the individual's control, so it was said) from the content of their shopping basket (courtesy of their supermarket loyalty card), to their daily exercise levels (through wearables or gym machines), to their relationship with their healthcare provider (numbers and kinds of visits, prescriptions, etc.). On hearing

this from a Microsoft executive at a 2008 conference, I wondered if my mobile phone would soon be delivering messages about the inadvisability of chocolate, given my BMI, just as I was reaching into the shelf in the store.

Sam told me that she read this on the flight over to the United States from the Netherlands and had startled her neighbor on the plane by laughing out loud. This is the kind of bittersweet example of the possible uses of context-sensitive, ubiquitous technology in health care that we both found fascinating, often confusing, and sometimes alarming.

Closely Observed Lives, Ill, and Well

Sam's recent paper, *Ubiquitous Digital Devices and Health: Reflections on Foucault's Notion of the 'Clinic'*,¹ pivots on a transition in Foucault's writing on illness, from the panopticon—where the central observer captures every move of the observed—to the clinic, which in a sense goes out to the “patient” (as often as not, someone who is not a patient) who is surrounded by the clinic or carries the clinic around with them. The context in which this is happening is a very broad shift in our conceptions of well-being, health, and care, and associated with these, responsibility and autonomy.

Health-and-social services are being conflated in countries with very diverse health care systems: the phenomenon transcends mere economics. This is just as evident in the United Kingdom, with its single-payer, tax-funded National Health Service (NHS), as it is in the United States, where the insurance-based, patchwork system defies categorization. I speculate too that it reflects a moral view that has come to be shared by the left and the right—for different reasons, perhaps—that the welfare safety net is not there to cushion those who are not willing to do something for themselves, but to help “those in genuine need.” Thus, we have the proliferating workplace “wellness” programs to accompany employer-based insurance in the United States, and we have

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Stuttgart · New York

DOI <https://doi.org/10.1055/s-0038-1666799>.
ISSN 1869-0327.

NHS Direct (and its successors) in the United Kingdom: *we provide the means by which you can take care of yourself.*

The trend may be driven by the seemingly inexorable economics of health care, with all the evident contradictions of a market-driven health care economy, but it also reflects a very benign and empowering trend in the relationships between providers and patients, and more broadly, the public. This has been expressed as a transition from the paternalistic era, when physicians—possessors of the power to heal—would do things *to* patients, through the still-present consumer era, where providers do things *for* patients, to an imagined future when an extended health system would do things *with* patients, would work with patients to improve their health and well-being. This future certainly has much to commend it: the consumer approach to health care may have dispelled the aura of the all-powerful physician, but it has also distorted behavior in many areas: physicians face parental pressure to prescribe antibiotics to children for self-limiting viral infections; opioids are dispensed for pain relief and has become a sick way of life; while the large TV ad cattleman carries Prilosec because he “won’t let heartburn stop him from enjoying what he loves.” Meanwhile, the obesity and diabetes “epidemic” expands its base while the “fat acceptance” movement shouts from the sidelines about the abuse suffered by the overweight and obese.

In economic terms, in any case, governments and health care industries must concern themselves with population health because that is the level at which policy can be implemented, expenditures managed, incentives, and disincentives provided. This is the realm of “nudge” rather than direction, libertarian rather than traditional paternalism.² It makes good sense to provide screening and prevention services—translating population principles to the individual—and, conversely, to give individuals the means to manage and improve their health, thereby reducing the volume of calls on the health services—achieving population aims through individual incentives. In a precursor to,¹ looking at surveillance complemented by “sousveillance,” Sam had already identified an element of risk in the active role of the patient as reflexive consumer. In evaluating the provider, one gives so much information that the patient can also be relatively easily identified.³

There is much to be said in favor of methods that increase our awareness of our health, enhance our well-being, connect us to others, and enlarge our sense of community. The intersection of the Quantified Self and Citizen Science movements promises much for engagement with our health and for potent intrinsic motivation to “take charge.” A potential extension of this through social media among “communities of practice” adds a virtual connection to friends with similar interests. This is all to the good.

There is a trade-off, however, familiar to all who have sacrificed privacy for convenience: my employer offers a generous incentive for me to link my fitness device to my health record, to ensure that I attend my annual wellness visit, and to maintain a healthy lifestyle by updating my exercise and diet diary. This is voluntary and, at this point at least, it does not take account of the actual *content* of these activities. (As I write, a cloud passes over my head, recalling

the innocent response “We only collect the metadata.”) But westward look, the land is bright: attached to this is an annual discount of \$600 on my health insurance premium. A cynic may say, this is the market value of my data.

To return briefly to the context from which I have taken Sam’s contribution to this debate: with her colleagues Nadezhda Purtova and Ronald Leenes, Sam edited a fine collection of essays on “The Interplay Between eHealth and Surveillance.”⁴ The tensions between the progressive moment of the energized individual taking charge of their well-being and health, on one hand, and the potential for surveillance on the other, are explored from a variety of viewpoints. Fittingly, the oft-taken for granted advantage of medical informatics over the laborious pen-and-paper methods of the past is appreciated, but unnervingly, one after another of these essays undermine our sense of progress. We see that our very inventiveness and adaptability make dupes of us as we integrate into our lives devices that report our location, listen whether we address them directly or not, memorialize habits and interests (witness the uncannily accurate advertising on the edges of Google searches), to say nothing of power of discovery when data sets are linked, such as the recognition of pregnancy through market-basket analytics at Target.⁵ Some of the essays tackle the problem in different settings—the elderly home, the workplace—and document the transition from early excitement to unease as the data builds up and the realization dawns that it is neither the individual nor the employer or care provider that “owns” the data, but a technology company that has unobtrusively intermediated this new relationship.⁶ The closing contribution, by Purtova, extensively reviews this question of ownership through the lens of the commons.⁷

Medication Adherence—“I know an old lady who swallowed a spy”

It is well known that problems can arise when a patient fails to complete a course of medication or misses an annual screen. “Nonadherence,” as it has come to be known in polite terms, is a problem not only for the patient in terms of ill health, but also for the health system when the cost of treatment exceeds the cost of prevention, or the second line of treatment is more expensive than the first. The transition from the paternalistic to the consumerist model of health care is reflected in the change in terminology: noncompliance has been reframed as nonadherence; what might have been seen as an order is now just good advice. Notwithstanding, there are good reasons to encourage patients to adhere to screening schedules and to prescriptions, and it also makes economic sense. Behavioral health programs are being explored to support patients who find health maintenance a serious challenge. The new field of “mHealth” has come into being to designate the full range of remote interventions, from calendar reminders and passive monitoring for the individual’s own use to active monitoring and reporting, triggering motivational messages or an alert that action may be needed—for example, when a patient’s movements and behavior, such as the frequency of calls he is

making, signals a possible transition to a manic phase in his bipolar disorder.

Dr. Lisa Rosenbaum has written about the most recent manifestation of mHealth, “digital health feedback systems,” such as that adopted in Abilify MyCite.⁸ This combines an “ingestible event marker,” that is, a transmitter incorporated in the pill, with a skin patch receiver which is in turn monitored by a mobile phone app. The event marker is designed to be activated solely by gastric liquids, so it is hard to fake ingestion of the pill. The initial trials are with mental health medications, as indicated, but it is anticipated that medications for other chronic conditions are likely to follow. As ever, this is not without clinical justification: a confused elderly diabetic who has had hypoglycemic episodes from forgetfully taking double doses of medications can use some help from a support system such as this. Dr. Rosenbaum makes the point that the hardest group of patients may be those who are in denial about their need for medication: “If the loss of our healthier selves is a bitter pill to swallow, that pill is no sweeter when embedded with a sensor!”⁸

This may be well meant, well designed, and sensitively used. A development which may, by combining economic considerations and the potential of digital health feedback systems, have a perverse result. Another means of monitoring medication adherence is through a dispensing device, such as an inhaler in the case of asthma medications. There are now several products offered on the market or at a planning stage that link each squeeze of the dispenser to a recorded dose that may be transmitted to a database and be seen by the provider. Could this lead to any harm? A parallel development to this, and one well adapted to address the needs of nonadherent patients, is based on biologics. Some of these come very conveniently packaged and need to be administered only once every 4 weeks or more. However, they are expensive and insurers do not lightly sign off on preauthorization unless they have some assurance that this payment would not go to waste. But what better way to ensure that the patient will make good use of the biologic than to know that the patient has a good record of adherence to current meds: enter the inhaler that records each dose. The potential for a Catch-22 is self-evident, and the moralistic note in this requirement cannot be missed: not merely that you have to be a “good” patient to deserve this medication. You do not deserve this medication precisely because you have been nonadherent in the past; although the biologic bypasses, and so obliquely addresses, the very behavioral health issue that results in nonadherence, that nonadherence rules you out for this medication.

Through our work to characterize the adult asthmatic population at one health system, I have had a glimpse of the complexity of human behavior in the face of a troubling chronic condition. It is not that the risk factors for exacerbation are surprising in themselves, but there is a genuine surprise, at least for a nonphysician, in what we found. For example, among the patients most likely to require an emergency room visit and hospitalization are many smokers. Smoking, I understand from the experts, is an act of denial—as well it may be. (“Asthma isn’t going to stop me living my

life.”) We do not deny life-saving treatment to would-be suicides. Why would we deny the most appropriate treatment to a nonadherent asthmatic?

Conclusion

In one of her last papers,¹ Samantha Adams considered at some length the dimensionality of the relationship between the physician-researcher (“knowledge creator” would be more apt), the patient, and medical knowledge. Reading Foucault, she differentiates spatial and temporal dimensions, as well as the concept space of medical knowledge. To this we may now add another dimension, that of “communicative” space (bowdlerizing a Habermasian term,⁹ for want of a better) in which communication is on an open channel, information is passively collected and transmitted to some imagined “clinic,” perhaps only a machine. The purpose of this transmission may be an immediate response—reminder, prompt, or warning—but more importantly, it may be a small increment to an accumulating body of information whose internal relationships, gradually revealed through analysis, constitute a kind of “knowledge without a knower.”

In Foucauldian terms, this seems not only to be a reversion of the medical gaze to a kind of blind panopticism, but it seems to replay Foucault’s analysis of state power as a transition from the harsh *city/citizen game* to the subtler domination of the *shepherd/flock game*. In his Tanner Lectures he asserted:

I’d like to suggest in these two lectures the possibility of analyzing another kind of transformation in such power relationships. This transformation is, perhaps, less celebrated. But I think that it is also important, mainly for modern societies. Apparently this evolution seems antagonistic to the evolution towards a centralized state. What I mean in fact is the development of power techniques oriented towards individuals and intended to rule them in a continuous and permanent way. If the state is the political form of a centralized and centralizing power, let us call pastorship the individualizing power.¹⁰

Surveillance seems to be an integral part of the city/citizen game. By contrast, the medical and fitness devices, the ubiquitous but unobtrusive communications add up to a “pastoral gaze.” Samantha Adams concluded her paper with four challenges. I hope that this framing of mHealth provides a space within which to address them:

- Are individuals placed in a state of “patientism,” wired up like intensive care cases, albeit invisibly and unobtrusively? Can they reclaim autonomy?
- Is the trend running against a humane resolution, less toward protection and more toward correction?
- What further changes may be experienced in the power relationships between providers and their organizations, technology carriers, and citizen stakeholders?
- How can individuals reclaim privacy—indeed, ownership, of their data?

Sam asked these questions, perhaps with greater subtlety, but not obviously with any greater optimism.

Funding

Anthony Solomonides has been partially funded by a grant from ThermoFisher for a project to characterize the asthmatic population at his institution.

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