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Keeping the person in the data:

Communicating care in the networked clinic



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Keeping the person in the data: Communicating care in the networked clinic

I have a friend with a medical file as thick as the Shorter Oxford English Dictionary, heavy with lab reports and images of her body captured through various technologies and scrawled diagnostic notes from the scores of clinicians she's visited. The content of the file finds its way to the physician she's about to see. But first, there is a series of forms to be filled, including those that provide identification and locate her in the socio-economic world: a mobile telephone number, an address, employment, insurance, and next-of-kin's details. Then she walks into an ante-room where a young paramedic spends a few minutes eliciting a brief history. The paramedic takes notes, but selectively, looking for specific details that relate (in her mind) to the "purpose of visit", a one-line description or question that drives the patient to this clinic. This piece of paper is added to the top of the file and sent to the physician in advance of the actual interaction. And so it begins, the clinical encounter. A few minutes of silence while the physician thumbs through the file that has been thumbed through many times before, her mind working back and forth between the patient in front of her and the data cloud she calls upon, to understand, to locate, and to project this particularity.

It's a three-point dance, between the embodied narrative of the moment, the abstracted storyline in the file, and the large meta-narrative of evidence that has been built by the millions of data points contributed by individuals with lives and experiences as disparate as the combinations of DNA that can never completely define them.

Having traveled across several systems of medicine with a problem that defies simple categorization, my friend is only too aware of the mental machinery that swings into action when she enters the clinic. She also perceives the numbers and notions that drive that machinery, inform its processes and frame its products. "Every system of medicine seems to think about data differently, breaks it down differently," she says. Over time, she has acquired the vocabulary and the grammar to shape her narrative within the data culture of a particular clinic, producing herself in a way that is recognizable to it.

As Lisa Gitelman and Virginia Jackson (2013) so evocatively put it, data are the starting point for "what we know, who we are, and how we communicate". In today's clinic, data drive the understanding and practice of health care.

In this paper, I argue that the dominance of data, in all its varied forms, creates a new dynamic that moderates and modifies clinical practice at various levels, shifting the dynamic of patient-provider relations, producing new forms of inequality and demanding therefore new forms of awareness and empowerment as well as possibly, new sensitivities to the practice of health care. The over-emphasis on the aggregate of medical knowledge—resident in the big data repositories that form the evidence base—combined with the dependence on diagnostic measurement, takes precedence over the experiential, the intuitive, the specific and the contextual. In fact, it takes the focus away from the embodied patient, who must then wrest back the clinical gaze and train it—with the appropriate data-framed articulation—back on herself. Ruckenstein and Schull urge scholars to explore how datafication is "unfolding across various digital divides (financial, technological, geographic)" (2017, p. 261); this paper makes the case for exactly such an exploration in contexts other than the Global North, where most studies of datafication have been situated. It also focuses on that aspect of the medical encounter where data can become a veil that obscures and devalues the present, even while its purpose is to clarify and explain.

Datafication in health: the big and the small

Even a cursory review of advertising in the health care sector—hospitals, pharmaceuticals, diagnostics, palliative and rehabilitative care, etc.—will point to the growth of what one might call a data mindset. Vocabularies of precision, accuracy and specificity abound, as the human body and its experience, as individual and collective, is rendered as a site of intervention and control, through measurement.

The datafication of health unfolds on a number of different scales and registers, including data-driven medical research and public health infrastructures, such as biobanks and governmental databases; clinical health care, as in continuous patient monitoring, implantable biosensors, the use of the Internet for doctor-to-patient interaction, and personalized or “precision” medicine—practices collectively described as digital health, eHealth, mHealth, or Health 2.0; and self-care practices, as in the use of direct-to-consumer genetic and microbiomics testing websites, health-related peer-to-peer social media, and a vast array of wearable fitness and health devices and smartphone applications (apps). (Ruckstein & Schull, 2017, p. 262)

The clinic, much like other institutions in the neo-liberal age, stands at the confluence of multiple forms of data (See Figure 1). Ruckenstein and Schull (2017) note that the technoutopian view of datafication in healthcare typically “emphasizes its potential to prevent and mitigate the physical and financial burdens” of disease and ill health but that “this vision is mostly speculative, promissory and as yet unrealized” (p262). They further observe that in the data regime, the data poor can be interpreted both as those whose data is not included in global repositories and those who do not have control over their data, and in this context, call for more research in emerging economies and lower income countries, particularly among culturally marginalized groups. “Health, considered from the standpoint of data activism, is a societal rather than individual issue, its meaning as political as it is existential.” (Ruckstein & Schull, 2017, p. 272) Other scholars, notably Dawn Nafus & Gina Neff (2016) point to the “extensive process of biomedicalization” and objectification of bodies that has resulted from such datafication.

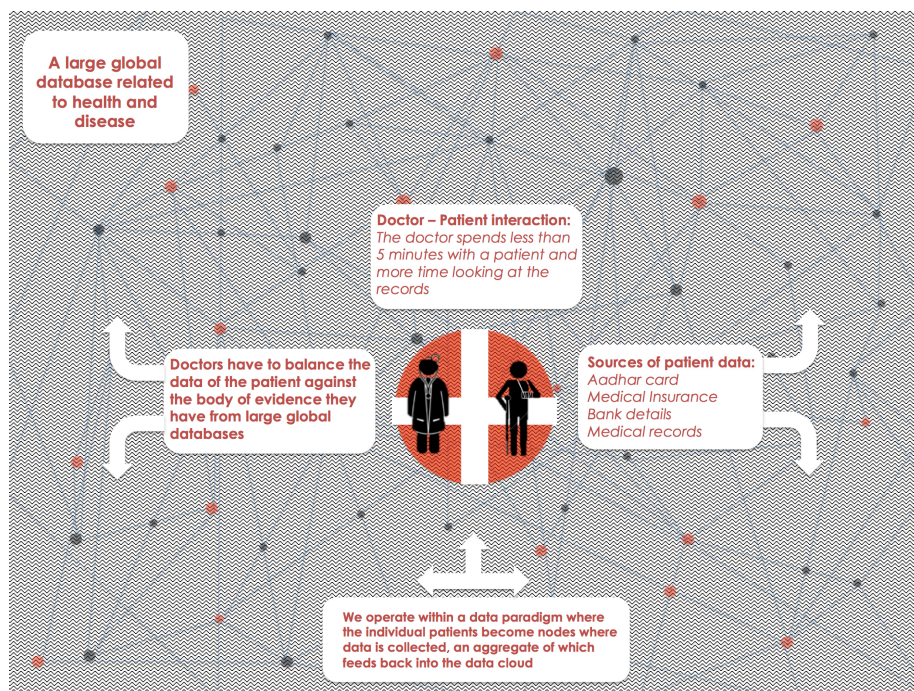


Figure 1: A large global database related to health and disease
(Image source: Neha Vaddadi for the author)

The datafication of health and wellness is part of the larger move or “turn” towards measurement and control based on information that is both voluntarily (or consciously) given by people and that which is harvested in more indirect ways, from the digital traces we leave as we live our lives and pass through different contexts. This has led to anxieties as well as expectations, which seem to be arrayed at opposite ends of a taut line stretched between dystopian and utopian visions of society. Gavin Smith (2016) points to three clusters of literature that have accumulated around these concerns: (1) studies and ruminations on datafied power including issues of surveillance and privacy, (2) explorations and analysis of what it means to live with data, and (3) data-human mediations. Of course, there is much that overlaps and travels between these clusters of scholarship, and newer foci are emerging as, increasingly, data sets are subjected to artificial intelligence tools and algorithmic manipulations.

In the broad area of health, discussions around datafication come together in a few distinct strands: privacy and data integrity, commodification, the politics of quantification, and algorithmic bias (in diagnostic, treatment and insurance decisions). My focus in this paper is not so much on data privacy as on data and information integrity and control, and the place of a subjective narration of experience that is increasingly excluded from the clinical encounter. Too often we see, in the anxiety to “fix” the patient in a diagnosable framework that facilitates efficient treatment, the health worker applies a predetermined logic to make sense of the various data points that congeal around the patient—some distant, some proximal, some self-generated, and some an extrapolation from the data donations of multiple others—comprising the evidence base, as it were.

Big data in health—meeting the criteria of volume, velocity and variety—are generated through multicentric clinical trials and other mechanisms of aggregation, including data harvested from social platforms, economic activity and government surveillance programs. Some types of data are anonymized and valued as instances of a phenomenon while others may be linked to various markers of identity, raising concerns around privacy and ownership. When collected from the *patient-as-client*, such data is gathered into the corpus of an institutional archive, the electronic medical records (EMR), and used as intelligence in multiple ways, from improving organizational efficiencies to strategizing which services to push and to what categories of people. When collected from the *patient-as-subject*, this contributes to research knowledge and contributes to the global evidence base. Both kinds of data require informed consent, but in a county like India (and perhaps elsewhere) the socio-economic and cultural gap that often exists between the provider and patient and the resultant power imbalance usually means that consent is often gained with little information exchanged or understood (Gitanjali et al., 2003). In this category is also included the large amount of information that resides in the many digital diagnostic devices that are fed with information from patients’ bodies, linked directly to individuals but also used in the aggregate, to discern patterns and possibilities. This includes data harvested in the course of routine examinations but governed by investigative protocols written to assemble normative data from different populations and sub-groups.

On the other hand, there is what we might call “small data”, both quantitative and qualitative—collected over the patient’s interactions with the health system, and used to incrementally construct the individual medical profile. This includes the “history” that, depending on the patient’s level of articulation, the health worker’s skill, and the organizational protocol, can range from a few cryptic sentences to detailed descriptions running into multiple pages. This history may have nothing more than the narration of a few symptoms, but it could also offer a detailed social and psychological profile when drawn out skillfully and read carefully. It includes the images, numbers and graphical representations from diagnostic tests. It could also include specific identifying socio-economic information, such as addresses, education level, family status, and ability to pay (covered by

insurance or other forms of social security). In India, increasingly, it may include the Aadhaar number¹ and a copy of the card itself. This data operates at two levels, from the healthcare worker’s perspective. It adds to the growing evidence base, doing its duty to the collective, while also collating information particular to the individual, thus giving the clinician what is needed for diagnosis in this instance. Many scholars have pointed to issues of privacy (Lupton 2012, Smith 2016) and consent (Gitanjali et al 2003) in the use of such individual data for the purposes of research and aggregation, and these concerns while important, are marginal to the scope of this paper. What becomes important to consider here is the ability of the care provider and the hospital system to connect the various bits of small data in a manner that attends to the whole of the patient.

Constituting the database: the what and the how

Small data form an important but often mis-applied bridge between the individual (the particular) and the aggregate (the general or the population level). An important element required to build this bridge is the patient’s experience, accessed through reflection and expressed through descriptive speech. In recent years, experience has also found its way into the sphere of data—through what Deborah Lupton (2014) calls the *patient experience economy*, which involves the extraction and aggregation of meaning, as well as the process of meaning-making, from patient accounts on blogs and social media, participation in support group web sites and comments in various forums. But in this extracted, distilled form, narrative-as-data can lose its explanatory and clarifying edge. Picture the clinician looking at the waves of reconstructed meaning on his computer screen instead of paying close attention to the waver in the patient’s voice as they tell the story of their body. The words may be caught, but the waver is often lost.

Datafication of the body is related to a longer “practice of numbering”, and scholars have sought to understand the “deep quantification of humans and their environments” (Lippert & Verran, 2018, p. 4). This no doubt has a bearing on the ways in which quantifiable data are generated, the logics by which they are analyzed and integrated, as also read, and becomes the often invisible and unacknowledged framework within which medical meaning emerges. The practice of numbering and the combinations of often incompatible number groups into a bundle that is then acted upon algorithmically is an important concern in health data, particularly in relation to understanding what Bates, Liu and Goodale (2016) have called “data journeys”. This approach, deriving from an STS perspective and to a large extent Actor-Network Theory, calls for us to locate critical data studies in health and other fields within contexts of data production, transmission, agglomeration and analysis, if we are to understand how it constructs and informs the “data gaze” (Beer, 2018), and to unravel the “semantic knots” (Lippert & Verran, 2018, p. 8) that can form at the intersections where numbers (as quantified data) move from one interpretive field to another.

Kate Crawford, Kate Miltner and Mary Gray, in an introduction to a special section on Big Data in the International Journal of Communication (2014), emphasize that a critical analysis of big data—or any kind of data—must ask the question: who and what is subject to analysis? The mythologies that are built around data—a kind of data fetishism, in fact—often veil the gaps and the fissures in what appears to be a comprehensive database. Apart from the technical aspects of the data—issues of categorization, grouping, analysis—there are also questions of completeness and diversity, and whether a database includes the full

¹ A Unique Identification Number linked to biometrics that is used in the disbursement of public welfare benefits and increasingly, as a requirement for bank accounts, cooking gas connections, mobile services, etc.

range of a given type, or indeed, all possible types. When applied to the health sector, this question becomes particularly crucial, as the evidence base that clinicians are so dependent upon, could have significant exclusions, in terms of people, conditions and contexts. They emphasize:

Questions of who is represented and how, necessarily lead to the political and social implications of big data research... How is the idea of the social reconstructed from big data logics? (Crawford, Miltner & Gray, 2014, p. 1668)

Further, we might also ask, what is the nature of the “social” that is “reconstructed”? The evidence base in any medical specialty is aggregated systematically from patients and through epidemiological studies but are limited in multiple ways. Hospital-based aggregations of data depend on those who access health care, while epidemiological ones are restricted by the scope and scale of data collection. Extrapolation and approximation are accepted tools to compensate for perfect granularity, and even within the world of medical practice, ethicists question the blind dependence on population-based evidence in individualized patient care (Goldman and Shih, 2011).

In a different but related context, Gitelman and Jackson (2013) note that “the imagination of data is in some measure always an act of classification, of lumping and splitting, nesting and ranking, though the underlying principles at work can be hard to recover.” (p. 8) It is important to note that classifications force approximations; they are creatures of convenience, not necessarily representations of truth.

Inclusion, representation, exclusion

So, we have here two issues: one, the body of data itself, the possible gaps and hierarchies within it; and two, the manner in which the data are organized to produce intelligence and inform decision making in an individual case. Nafus and Neff (2016) see this widespread harvesting and use of personal health data as part of a broader trajectory in medical research and care that involves a number of practices and technologies that exist along a continuum, from laboratory analyses of body fluids to imaging techniques from the X-Ray to the CAT-Scan to health-tracking wearables. As Lupton (2014) notes:

The metrics derived from digital databases make visible aspects of individuals and groups that are not otherwise perceptible because they are able to join-up a vast range of details derived from diverse sources. Individuals and social groups or populations are thereby rendered into multiple aggregations that can be manipulated and changed in various ways depending on what aspects are focused on or searched for. (p. 859)

But another thing happens with this *body of data of the body*—while it is the deviances from the “normal” that are signposts of disease, the building of the “normal”—the normative database itself—depends on data drawn from a large mass of individuals who do not have disease—the so-called *normals*. Recalling Nafus and Neff’s (2016) exhortation to pay attention to data *from whom and for whom*, we see that this normative database draws on a very narrow range of human subjects, simply because of availability. In any ethnically and culturally diverse population, to build a truly representative normative database that is context and culture inclusive, as one might imagine, is a gargantuan task.

Consider, then, the case of a tribal woman from a remote hilly region in India who enters a clinic for the first time. Her community is under-represented, if not absent, from the normative database. She exhibits a medical peculiarity whose experience is rendered in a language unfamiliar to the primary care physician who is most likely not from the region.

Her file grows thick with the data harvested from her body, as she—it—is tested and imaged and measured through available diagnostics. But her history sheet is thin, as the young para-medical cannot elicit words that render the story familiar, in a way that could be read against the base of available evidence.

Such an instance also leads us to wonder about the politics and meanings of data-resistant bodies that communicate in non-hegemonic forms, as opposed to the data-compliant body that is easily harvested for information. Payal Arora (2019) notes that the project of digitizing identities, specifically in the context of Aadhar, has been “particularly disadvantageous to the very people it intended to empower” (p. 9). Ursula Rao, while taking note of both “empowering and exclusionary aspects” of the technology being India’s UID project, describes the inability of the biometric readers to capture data from the calloused or burnt fingers of those engaged in manual labour, with agents having to “twist and turn the uncouth bodies of homeless citizens to create decent data sets” (Rao, 2013, p. 74). She goes on to outline instances of non-compliant women’s bodies, where the problem was “less physical and more habitual”, with women resisting “the intrusion of the deep gaze” of the iris scanner (p. 74). Narayanan and Dhorajwala (2019), emphasizing precarity of data-managed governance, draw on a case of mistaken digital identity, where a biometric datapoint was linked to the wrong bank account, to make the point that digital identities can become erroneously built composites.

Even as these instances relate to non-medical contexts, they point to the difficulties inherent in capturing data from bodies and the culturally embedded nature of the very act of measurement. It may be safe to assume that biomedical instrumentation in the high-tech clinic would be more sophisticated and sensitive to a range of material conditions and there would be greater attention paid to the integrity of data assemblages, but these examples do indicate that for less aware, exposed patients who come from society’s margins, there may always be frictions as they are rendered into such assemblages.

Bodies and data in the clinic

One of the consequences of the data-led discourse in health care is that it has seeped into the ways in which we think of and describe our bodies, and how physicians look at and understand our symptoms. We experience and know our bodies in particular ways, but we must articulate that knowledge and experience in the dominant language of the clinic which is, increasingly, represented in objectivated terms, as data. Smith & Vonthehoff (2016) note that even though we may believe that attention to the organic body is the primary means to self-knowledge, contemporary means of sensemaking are “increasingly outsourced to and performed by auxiliary codifying mechanisms that are adjudged to encompass greater degrees of validity and reliability.” This, they say, “raises important sociological questions pertaining to contemporary experiences of embodiment, especially the displacement of ‘feeling representations’ to digitised sensemaking infrastructures that become primary oracles of the objectivated body” (p. 5).

Deborah Lupton (2013) echoes this, noting that the use of visualization and measurement technologies has led to a significant shift in how the body and health are conceptualized, articulated, and portrayed. “Where once people relied upon the haptic sensations they felt in their bodies and reported to their physicians, medical technologies devoted to producing images of the body have altered the experience and treatment of bodies.” (p. 6) Lupton sees this as having resulted in greater validity being given to these once-removed forms of information rather than on the patient’s description of their “fleshy bodies”.

What does all this mean for the clinical encounter? There is the medical practitioner or the health worker, who has been trained to read the individual as a “presentation” of data which is then weighed against the large base of evidence that has been amassed through research. There is the data itself, numerical, visual, narrative, packed into various forms that can be called upon to frame and augment intelligence. There is the context of the clinic, a space designed to distance the self from the body, with its various surveillant data-gathering apparatus (Mocherla, Raman and Holden, 2012). There is the patient, one of a multitude of individuals, each unique, yet each an instance of a particular combination of data points. Patients may be “digitally engaged”, as in Lupton’s account (2013), bringing their own data into the room, capable of accessing and using the vocabulary of measurement drawn from their wearable devices and their practices of self-monitoring. It is possible to imagine that there may be a skewing of attention, even comprehension, in favour of such a digitally engaged and articulate patient—a patient that the increasingly data-socialised medical practitioner knows how to slot. The tribal woman with a poorly documented and thus only faintly recognized condition, coming from an unfamiliar context, loses out on multiple counts.

When networking intensifies, along with the dependence on distantly aggregated data from multiple medical, social and economic sources, new problems arise. Gina Neff (2013) has emphasized “social interoperability” of data and the need to integrate an acknowledgement of this into health solutions—which currently does not always happen, particularly in developing country contexts where lack of regulation and awareness makes such interoperability—and the assurance of integrity—difficult. This also compromises what Helen Nissenbaum (2010) calls contextual integrity—primarily in relation to privacy, but also in relation to selfhood and the right to claim and position one’s own embodied narrative. Both these ideas speak to the need to pay attention to context, or rather, for data to be read *in context* as well as *across contexts*, with the active and informed engagement of patients, to the extent possible. Medical data about the body, thus, would necessarily require collaborative interpretation against social and cultural contexts by both patient and clinician in ways that maintain such integrity and facilitate meaningful interoperability.

Data and health identities

In the context of social work in Britain, Evelyn Ruppert (2012) speaks of issues that arise with information resident on multiple databases resulting in “many versions” of people, moving from a narrative to a database way of thinking. We need to think then how this works in the context of health identities, which Fox and Ward (2006, p. 462) define as “features of the clustering of relations around specific aspects of embodiment, such as sport and exercise, body modification, disability or growing old.” Even within the space of health, one might imagine, several intersecting identities are possible (chronic conditions intersecting with seasonal ailments and issues of mental health and trauma, for instance).

What then are the implications of this data regime—and the privileging of certain kinds of data collected, categorized and analyzed in specific ways—for the clinical encounter?

Medical professional Trisha Greenhalgh writes in the BMJ, many years before data became the “megafauna” of social research (as boyd and Crawford put it) about the fallacy of misplaced correctness that arises when data are read “verbatim” and the truth of the aggregate is taken to be the truth of the individual case.

How, then, can we square the circle of upholding individual narrative in a world where valid and generalisable truths come from population derived evidence? My own view is that there is no paradox. In particle physics the scientific truths (laws) derived from

empirical observation about the behaviour of gases fail to hold when applied to single molecules. Similarly (but for different reasons), the “truths” established by the empirical observation of populations in randomised trials and cohort studies cannot be mechanistically applied to individual patients (whose behaviour is irremediably contextual and idiosyncratic) or episodes of illness. (Greenhalgh 1999, p. 324)

Greenhalgh emphasizes that genuine evidence-based practice must draw from an interpretative paradigm where the unique and contextual ways in which a patient experiences illness become central, and then weighed against the information available from clinical trials as well as the doctor’s own experience—thus drawing on the distinct subjectivities of the patient and the doctor. This is particularly important in a context where a neo-liberal rationality dominates, with its emphasis on generalizable frameworks that privilege efficiency and ‘return on investment’ of resources, including clinician time and attention. Physicians are often under pressure to justify decisions on the basis of data drawn from diagnostic instruments that the system has invested in and to document such decision making for medico-legal contingencies. In such cases, data-based objectivity, which draws on documented evidence, is privileged over experience-informed subjectivity, where patient narratives and physician subjectivity are hard to fix meanings on.

Gina Neff has also noted:

“Many of the most exciting new tools to date have been designed without considering how doctors and patients communicate. Before we can talk about the integration and analysis of multiple data sources in electronic health records, we must figure out how these data can be used by patients with their doctors for their joint decision making in practice.” (Neff 2013, p. 120)

Drawing patients into the decision-making process has always been a challenge, depending on clear and empathetic communication between care giver and care seeker, and where this communication is moderated by an additional layer of abstract information, it becomes even more difficult to create a shared understanding that balances experience and data.

Patient empowerment in the datafied clinic

A useful way of thinking about the clinical encounter in these datafied times is to adapt Ball et al.’s (2016) notion of proximal spaces, and take their advice to pay attention to the competing normativities in this space. The proximal brings into conversation multiple subjectivities and interacting contexts—the medical, the social, the personal, the aggregate, the experiential, as well as the materiality both of body and data. The medical professional must then attend to the ways in which these normativities can be applied to a collaborative process of meaning-making that combines various forms of information. The patient, on the other hand, must be empowered to not only articulate their embodied experience in ways that speak to the data regime but also critically question its exclusions, inclusions, and applications.

Marent et al. (2018) introduce the idea of ambivalence in the context of digital health design, as a way to introduce nuance and an acknowledgement of the embedded nature of patient experience, in what can otherwise become a reductive use of “objective” medical data. They show, through data gathered in co-design workshops, “how positionings towards quantified data, digital connections and instant alerts are *related to and balanced within* situated practices.” (Ibid, p. 4) Further, they note, “By connecting opposing

orientations in an ongoing manner, ambivalence can increase reflexivity and give rise to forms of agency that defy narrow decision-making frames.” (2018, p. 6).

The literature thus points to a range of concerns emerging from the use and application of data in the clinic, in particular when data become the primary mode of seeing, assessing, documenting, and understanding the patient. These concerns range from issues of privacy and ownership of data, to transparency in decision making and a sidelining of embodied experience.

Given these concerns, I propose three major areas where those interested in data justice in the health care context may focus critical research and advocacy efforts at the level of policy, practice and patient community:

The **first** of these must examine the systematic exclusions in the building of medical/health datasets upon which decision-making rests. This means pushing the data-gatherers to acknowledge and address gaps in the datasets built and used, which have the effect of producing data-rich and data-poor communities and groups. As Deborah Lupton (2013) notes, lack of data can make subjects as vulnerable in relation to power as when their data is included. This means looking at what goes into building normative databases, to the logic behind the algorithms that turn these data into knowledge, the training sets that are used to build artificial intelligence diagnostics. This also means building a healthy level of data skepticism among health care workers, a skepticism that can become part of the clinical protocol in diagnosis and treatment. Those who draw on data to support decision making, therefore, must call on this skepticism and apply notions such as ambivalence as they balance an understanding of the general with the particular embodied presentation of the patient.

Jonas Lerman, in an essay that talks about what he calls the principle of “data antisor-dination”², draws our attention to the exclusions of big data, exhorting us to acknowledge those who are sidelined by the practice of datafication.

[T]here is another type of error that can infect datasets, too: the nonrandom, systemic omission of people who live on big data’s margins, whether due to poverty, geography, or lifestyle, and whose lives are less “datafied” than the general population’s. In key sectors, their marginalization risks distorting datasets and, consequently, skewing the analysis on which private and public actors increasingly depend. They are big data’s exclusions. (Lerman, 2013, p. 57)

The physician engaging in the clinical encounter must then be sensitive to the possibility of such exclusions as she attempts to draw from the evidence base to make judgments about the patient before her. Additionally, Kelly and Noonan (2017) discuss the importance of understanding practices of datafication, particularly in relation to public health, in a manner that ensures that we do not “unbundle data from the practices that constitute them” (p. 873). This calls for an awareness not only of how databases are built (what populations they cover and what they leave out) but how data are made (what measurements or processes are used to render data)—a tall order, no doubt, but necessary if we are to not succumb to a totalizing data logic.

The **second** relates to closing the gap between those who are extremely data aware and those who are data blind in a way that it evens the scales in the clinical encounter. This is

² The legal principle of anti-subordination actively counters state institutions and practices that enforce secondary social status on historically oppressed groups, and in relation to big data exclusions, data anti-subordination would actively account for the invisibility of groups with “light data footprints”. (Lerman 2013; 61)

not to say that patient and provider education is the only solution, but it is important to move away from what Gina Neff calls a “numerical ontology” (Neff 2013), and one way of doing this is to get the best from measurements of the body while recognizing their limitations. Neff points to the privileging of the quantifiable and measurable over the hazy and ineluctable. Lupton also notes that the digital health phenomenon, as it configures the ideal of the digitally engaged patient, seeks to privilege the body that is measured, monitored, quantified and visualised in ever greater detail through the efforts of the patient (through self-tracking) as well as healthcare professionals (through reliance on diagnostic tests and the evidence base) (Lupton, 2014, p. 860). If it can’t be measured, how do we talk about it? If it can’t be measured, how can we trust it? Is it even real? Or even if real, is it important? The question for us—and for us as patients—is, how does one discover and use a vocabulary that can counter the numbers that sensors provide? Marent et al.’s study (mentioned earlier) it was found that there was a need to distinguish between “getting data” and “being informed” (2018, p. 11), suggesting that simply providing access to numerical or quantified data is not sufficient but efforts need to be made to help patients understand how to read and contextualise their own medical data. Some participants in this study saw quantified data as a “reduction” that requires “careful interpretation”. Marent et al. point to other literature in HIV care that confirms that there are multiple meanings assigned to such quantifications as viral load and other numerical parameters that require discussion within the broader context of the patient’s health experience. While their argument focuses on the need to carry out such conversations face-to-face rather than through digital health platforms, their finding also underscores the importance of acknowledging ambivalence in reading health data. Their study suggests that patients’ relationship to data might vary across conditions and be modified by other socio-cultural factors, such as age, life situation, education, and comfort with technology in general. Some participants in their study also resented the ways in which digital health platforms that “push data and alerts might constantly confront them with an imposed reality of their disease”, suggesting that subjective experience must have a place in the clinical conversation.

This is not to dismiss the value of data. As Smith and Vonthehoff discover in their study of the Quantified Self (QS) community, those who are data aware are actually able to use the language of self-tracking and quantification to “challenge the aggregated definitions ... favoured in medicalized discourses of health.” (Smith & Vonthehoff, 2016, p. 4) Thus self-tracking (and knowing the self through data) is about “not only the stories people tell themselves through their data, but also the stories and types of selves they exhibit publicly.” While some have critiqued the practice of self-tracking as contributing to the creation of algorithmic identities that depend on numbers: the QS phenomenon has shown that such data can “morph into selves”:

Data in these types of self-tracking practices are a new element in an aesthetic and continuous process of identity construction. It is not just used to learn about oneself but also to construct stories about oneself.... Understood as a narrative and communicative practice, self-generated data may thus enable the social sharing of private experiences and mediate between subjective experiences of physical or mental health and more objectifying framings of health and ill-health. (Sharon and Zandbergen, 2016, p. 11—referring to Jenny Davis’ 2013 work on the quantified self).

But clearly, those who can tell such data-rich stories have an advantage over those who do not, and that is a disadvantage that needs to be addressed by health providers as well as educators and patient rights advocates.

This leads to the **third** area, which relates to capacity building to bridge the gap between those who are data articulate and those who are data illiterate and lack the ability or the tools to participate in the datafied discourse. Deborah Lupton (2012a, 2013) suggests that

such tracking endows individuals with a form of agency, allowing them to draw on data from tracking devices speak about their bodies with a level of authority, thus balancing the clinician-patient equation to some extent. Patient education efforts must expand to demystifying diagnostics, developing an understanding of what the numbers mean and what they can and cannot say, and the vocabulary of data. In many countries in the West, patients do not have direct access to their records, making it even more difficult for them to speak through and with their own data and reconcile it, if at all possible, with their experience of ill health or disease. In other contexts, such as in India, patients have direct access to all their diagnostics, but often lack the knowledge to interpret the numbers, much less question them.

Conclusion

Evgeny Morozov (2013) strikes a note of caution when he says: “Human experience, run through the quantification mill, is reduced to little more than a stream of silent and mind-numbing bytes” (p. 256). True, quantification is reductive, but it also offers a way of drawing actionable meaning from large volumes of information. Collective experience does have something to teach us, as even data-skeptics would admit, and the patterns that might become evident by applying the tools of statistical analysis and now, artificial intelligence, to large amounts of data can give us valuable insights into phenomena. But we need ways of navigating the datafied terrain, ways that allow us to continue to keep alive other kinds of insights, and ineluctable experiences that may not be possible—or even desirable—to render into data. The body is, after all, a thing that has an irreducible *thinginess* despite the myriad means of making its parts readable. And within the body is the self, knowable only by the self, through feeling probes directed by the mind. So even while medical practice continues to amass data and turn it into a form of actionable knowledge, practitioners need to retain trust in the patient’s ability to articulate and make meaning of their experiences, while patients need to trust their instincts and acquire a vocabulary that can communicate self-knowledge in a way that uses and complements experience that goes beyond what is rendered as data.

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