



Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Special Communication

Can a collaborative healthcare network improve the care of people with epilepsy?

Ejaz A. Shamim^{b,c}, Ketan Mane^{a,c}, Tobias Loddenkemper^d, Alan Leviton^{d,*}^a Mid-Atlantic Permanente Research Institute, Kaiser Permanente Mid-Atlantic States, Rockville, MD, United States^b Mid-Atlantic Permanente Research Institute, Rockville, MD, United States^c Mid-Atlantic Permanente Medical Group, Kaiser Permanente, Rockville, MD, United States^d Department of Neurology, Boston Children's Hospital and Harvard Medical School, Boston, MA, United States

ARTICLE INFO

Article history:

Received 15 February 2018

Accepted 16 February 2018

Available online xxxxx

Keywords:

Data collection

Improving health care

Information technology

Networks

Electronic medical record

ABSTRACT

New opportunities are now available to improve care in ways not possible previously. Information contained in electronic medical records can now be shared without identifying patients. With network collaboration, large numbers of medical records can be searched to identify patients most like the one whose complex medical situation challenges the physician. The clinical effectiveness of different treatment strategies can be assessed rapidly to help the clinician decide on the best treatment for this patient. Other capabilities from different components of the network can prompt the recognition of what is the best available option and encourage the sharing of information about programs and electronic tools. Difficulties related to privacy, harmonization, integration, and costs are expected, but these are currently being addressed successfully by groups of organizations led by those who recognize the benefits.

© 2018 Elsevier Inc. All rights reserved.

1. Introduction

This is a plea for cooperation to improve the care of our patients. Some of the tools that can help us achieve this goal will be enhanced by having access to the big data that are in electronic health records (EHRs). We are not talking about health information exchanges that allow the emergency departments of local hospitals to have access to the office records of your patients [1]. Rather, we want to encourage greater participation in collaborative healthcare networks (otherwise known as learning healthcare systems) where you (and your patients) can benefit from access to “big data” [2] and to health systems that help manage patient care and care integration.

The more each of us can be part of consortia of institutions that share their data, the larger the pool of available data and the greater the likelihood these data can be transformed by data mining techniques into clinically useful information. Our plea is to give serious consideration to encouraging your institution to become part of a network that can allow continuous evolution of care strategies and provide information about available data sets and treatment failures and successes and to have a channel for rapid dissemination where we learn from each other about best practices. This will allow you access to some of the new tools increasingly available to assist physicians with advances in machine learning, artificial intelligence, and computational neural networks.

* Corresponding author at: Boston Children's Hospital, 84 Sumner Street, Newton, MA 02459-1958, United States.

E-mail address: alan.leviton@childrens.harvard.edu (A. Leviton).

The value of participation in a network can probably be estimated from three laws that were introduced when telecommunication developments were in their infancy. Amara's law states that “We tend to overestimate the effect of a technology in the short run and underestimate the effect in the long run” [3]. According to Metcalfe's law, “the value of a (telecommunications) network is proportional to the square of the number of connected users of the system (n^2)” [4], while Reed's law postulates that “the value of a network increases dramatically when people form subgroups for collaborations and sharing” [5].

Because our plea might be seen as special pleading for a collaborative change, we acknowledge upfront our own interests in the visualization of seizure occurrence over time, patient-input of data, the epidemiology of epilepsy, quality improvement, comparative effectiveness, clinical decision support, seizure recurrence prediction, refractory seizures, sudden unexpected death in epilepsy (SUDEP), and multicenter collaborative research. We are likely to benefit if we had access to data in expanded networks.

2. Background

The Institute of Medicine (IOM) defines a “collaborative healthcare network” as one “designed to generate and apply the best evidence for the collaborative healthcare choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care” [2].

<https://doi.org/10.1016/j.yebeh.2018.02.018>

1525-5050/© 2018 Elsevier Inc. All rights reserved.

Please cite this article as: Shamim EA, et al, Can a collaborative healthcare network improve the care of people with epilepsy?, *Epilepsy Behav* (2018), <https://doi.org/10.1016/j.yebeh.2018.02.018>

To encourage progress along this path, the National Institutes of Health launched the Big Data to Knowledge (BD2K) initiative in 2012 with the goal of promoting “development of innovative and transforming approaches and tools to maximize and accelerate the integration of Big Data and data science into biomedical research” [6].

The Patient-Centered Outcomes Research Institute (PCORI), funded through the Patient-Centered Outcomes Research Trust Fund (PCOR Trust Fund established by Congress through the Patient Protection and Affordable Care Act of 2010), in turn, funds relevant studies. One such project funded by PCORI is the Scalable Collaborative Infrastructure for a Learning Healthcare System (SCILHS, <http://www.SCILHS.org>) clinical data research network, which enables “a queryable semantic data models across 10 health systems covering more than 8 million patients, plugging universally into the point of care, generating evidence and discovery, and thereby enabling clinician and patient participation in research during the patient encounter” [7]. Yes, 10 learning healthcare systems. That is the type of network we are talking about. “The world is moving towards learning healthcare systems” [8].

“One has only to consider the birth of the internet (the ultimate information commons) from thousands of interconnected open source software projects to realize that an information commons provides a wellspring of new ideas” that can drive innovation and make linked organizations more effective [9]. Indeed, the more open and the larger the information commons, the greater is the potential to provide benefits for all [10]. Combined with comparative effectiveness modeling and machine learning as well as artificial intelligence learning techniques, such a learning healthcare system offers the promise of being able to continuously find better treatments for individual patients and model outcomes in patients or groups of patients.

“What gave *Homo sapiens* an edge over all other animals and turned us into the masters of the planet was not our individual rationality, but our unparalleled ability to think together in large groups” [11]. “When they work well, consortia act as catalysts, to accomplish what members cannot do alone” [12]. Among the advantages of large networks are increased opportunities to benefit from (internal) crowdsourcing [13] and recent and relevant clinical data (v.i., see clinical decision support) [14]. Available progress in internet and connected collaborative platforms now provides the backdrop for even better sharing and exchange of information and experiences.

3. Digital health

A 2012 World Economic Forum Council Report, “Harnessing the Transforming Power of Digital Health,” included the following words: “Unfortunately, healthcare has been slow to adopt the use of information and communication technologies – digital health – and risks falling further behind. As a result, there has been a lack of productivity improvement in healthcare, which stands in stark contrast to robust growth in other sectors of the world economy. ... Digital Health has the power to radically change the global health landscape – making it better and more efficient” [15]. Others have used the words, “data-driven healthcare” and e-health to describe the harnessing of data to improve healthcare.

Digital health is a natural offshoot of a global information commons with potentials that we have yet to fully recognize because of hurdles such as financial sustainability, patient confidentiality, data sharing agreements, and standardizing the information collected (data elements). Our hope is that these hurdles will be overcome with cooperation, common goals, and such incentives as improved care and outcomes, streamlined care options, improved patient and physician satisfaction, and cost savings (achieved by reducing/eliminating unnecessary or ineffective treatments).

4. Benefits

Many electronic tools currently available to you enhance your ability to care for patients. Here, we want to emphasize the benefits that accrue

from the expanded network, some of which are electronic tools more readily available from a large network than from a smaller one. Most of these reflect economies of scale, while others are probably a consequence of critical mass phenomena. In addition, however, we want to emphasize the value of the enlarged database that has the potential to provide more valuable clinical decision support than can be provided by a smaller network.

5. Whose benefits?

Before we discuss the benefits of a learning healthcare system, we need to ask, “Whose benefits?” According to an IOM report, patients, providers, economists, payers, and employers each have different perceptions of value [16]. Patients want access, shared decision-making, clear communication, reduction of their suffering (pain, emotional, cognitive, and functional impairment), convenience, and maximizing their health-related quality of life [17]. Others see “unique preferences, concerns and expectations each patient brings to a clinical encounter and which must be integrated into clinical decisions if they are to serve the patient” [18]. Some patients are likely to appreciate increased availability of information about their care. We anticipate that some patients will appreciate the opportunity to provide data electronically that are likely to contribute to improved care.

Providers tend to assess value on the basis of appropriateness of care and effective, evidence-based interventions [19] while economists, payers, and employers define value on the basis of the benefit achieved for the money spent (i.e., “outcomes relative to costs”) [20]. The Centers for Medicare and Medicaid Services are replacing fee-for-service reimbursements with what are deemed “value-based” payments [21].

6. Benefits and how they are achieved

Here, we take the view that what benefits your patients is likely to benefit you and society. Of course, the benefits might not accrue equally, but the concept that we all benefit is the one we ask that you keep in mind.

Some who promote learning healthcare systems (including components and attributes, such as systems medicine and personalized medicine) have identified goals patients and physicians could agree on. One set has been called P4 medicine because it emphasizes prediction, personalization, prevention, and participation (of both patient and physician) [22]. Subsequently, the P4 model of healthcare has been expanded to become the P5 model, which adds psychocognitive goals [19]. Learning healthcare systems can have a patient-centered orientation that can be enhanced by both patients and physicians [23].

Ideally, what benefits patients and physicians also benefits health plans and other institutions that provide care. The result can be best practices, clinical practice guidelines, and care pathways that are continuously or intermittently evaluated and updated [24].

6.1. Improved quality of care and improved safety

Efforts are currently underway to improve communication between families and physicians [25], to improve the quality of seizure care and safety in the community [26], to increase the availability of information available to women with epilepsy who are pregnant [27], to improve the quality of life of people with seizures [28], to reduce the seeking of emergency room care for recurrent seizures [29], and to improve the quality of care and safety in epilepsy monitoring units [30]. Representatives from different institutions have contributed to each of these efforts to improve epilepsy care.

We all want to do better and the learning healthcare system facilitates efforts to do so. The availability of data from many patients allows gathering of data on physician performance (number and type of patients seen, tests ordered, drugs prescribed, duration of intervals between follow-up visits, referrals, performance in keeping with recommended guidelines,

Download English Version:

<https://daneshyari.com/en/article/8683632>

Download Persian Version:

<https://daneshyari.com/article/8683632>

[Daneshyari.com](https://daneshyari.com)