Finding the Humanity in Healthcare Data: Visualization for Communicating Health

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Wherever the art of Medicine is loved, there is also a love of Humanity — Hippocrates

Abstract

Provider–patient communication is crucial in healthcare, and has been overlooked and even harmed in the rush to digitize medicine. Visualization can deliver the meaning of medical data clearly, revitalizing the provider-patient relationship. As evidence of this potential, we review visualization's historic and rapidly growing communicative role, both broadly and in healthcare. We conclude with several questions that merit further research.

Introduction

The digital revolution has reached health, promising increased efficiency, quality and well-being. Revolutions typically promise improvement, but they also bring disruptive pain, at least temporarily. In health, much of this pain focuses around data: the insatiable need for it, and the necessity of putting it to good use.

To meet its data demand, medicine has adopted electronic health records (EHRs), which are creating much of the industry's transformative pain. While EHRs are helping the health industry create data at unprecedented scale, data entry is still too disruptive, and the data itself has not yet brought enough benefits to alleviate the pain. In search of these benefits, the industry has recently turned to visualization, but doctors report the continued decline of the doctor-patient relationship, a keystone of healthcare for millennia.

Is data inherently dehumanizing? Will visualization be only a minor player in medicine's continued transformation? These fears may yet prove true. But recent research suggests that data and visualization can be adapted to support the intensely personal relationships at medicine's core, bringing sympathy back to science, and using data to deliver both warmth and well-being.

EHRs Are Pervasive, and Their User Experience is Dismal

Recent changes in US health regulation have strongly incentivized the use of EHRs, and today at least 78.4% of US office physicians use them[1]. EHRs promise improved efficiency, quality of care and health[2]. However, recent research indicates that little progress is being made toward these goals[3], with one survey of the American College of Physicians finding that on average, attending physicians lose 48 minutes per day, or 4 hours per week to EHRs[4]. In another survey, a large majority of physicians disagreed with the suggestion that EHRs help them see more patients per day, and nearly half felt that their EHR did not help them provide better patient care[5].

Not only is the utility of EHRs in question, their user experience is in crisis. A California survey found that 27% of physicians were dissatisfied with their EHR[6]. A national survey painted a more alarming picture, with less than half of physicians enjoying working with their EHR[5].

Perhaps most important, EHRs may be harming the doctor-patient relationship, which is central to quality of care[7]. A 2013 study of internal medicine interns found that they spent only 12% of their time interacting with patients, and 40% of their time interacting with computers[8]. In a national survey, a large majority of physicians felt that EHRs reduced their ability to focus on patient care[5]. A Portuguese survey had similar results[9]. As one doctor put it[10]:

> So in the mind of the physician, a lot of insight is missing as a result of less direct communication with the patient and less ability to freely express one's thoughts. Symmetrically, the patient feels less direct contact and is often disturbed by the doctor's pecking on the keyboard and looking at a screen. The sense of not being heard or understood is often prompted by this distracted, electronically fettered encounter.

Interestingly, the few studies to examine EHR impact on the patient side of the relationship indicate that it is positive[9,11], with patients reporting improved eye contact and rapport with providers. EHRs may structure communication usefully, without being designed to do so. However, these studies do not measure the accuracy of the knowledge gained by patients in their interactions, nor ask patients to consider that EHRs have shortened those interactions.

Charles Babbage, who with Ada Lovelace invented the computer in the 1800s, said it first: garbage in, garbage out. As currently designed, most EHRs are primarily tools for gathering data, and have lost track of the humanity at medicine's core. They are difficult to use, annoying, and neglect the personal interactions that happen around them. Until that changes, many providers will input medical data only grudgingly, and without the best data, EHRs will fail to realize their full potential.

Visualization Can Help

Although solving the problems of EHRs will require a broad range of techniques and talents — particularly those from usability and user experience — visualization will certainly play an important role. Indeed, medicine was one of modern visualizations earliest motivating applications[12], and medical visualization dates back to the foundations of health science, when Dr. John Snow mapped the cases of a London cholera epidemic[13] (Figure 1), and Florence Nightingale plotted deaths in the Crimean War[14] (Figure 2).
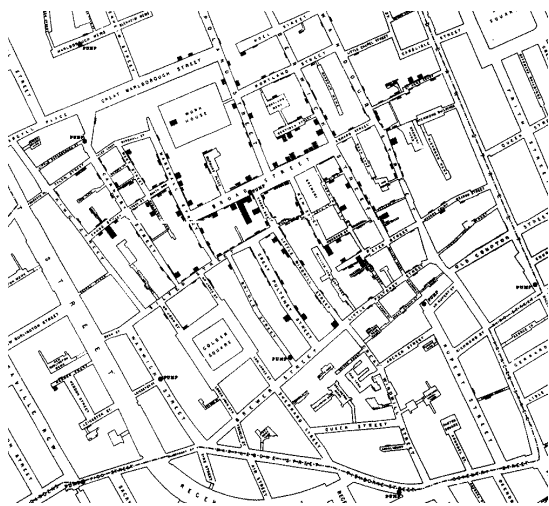

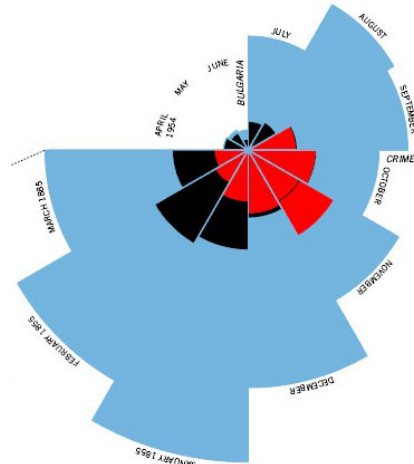**Figure 1:** John Snow's 1855 cholera map.

Figure 2: Nightingale's 1858 plot of war deaths.

Given this history, what might visualization still have to offer to medicine and its EHRs? To date, most visualizations have been tools for creating meaning from data. Familiar medical examples include X-ray, CAT and MRI scans, used by doctors to understand the condition of their patients. Yet these same scans are poor tools for communicating that understanding to patients, who do not have the training to interpret them.

Unlike many other scientific disciplines, medicine cannot be practiced effectively without communicating with the broader public — that is, with medical patients. Indeed, according to Shachak & Reis[15] (quoting Engel[16]), "communication is one of the 'most powerful, encompassing, and versatile instruments available to the physician,' " and EHRs should strive to support it. The studies of patient experience with EHRs we referenced above[9,11] hint at this potential, but this beneficial communicative impact is poorly understood.

To begin addressing the shortcomings of EHRs, medical visualization should become a tool not just for discovery, but also for communication. Below, we illustrate the promise of visualization in this communicative role by reviewing research on visualization for communication in general, and medical communication in particular.

Visualization Has Become a Communicative Tool

Visualization has found increasing use over the last several years as a communicative tool in publishing, including both traditional outlets such as the New York Times[17] (Figure 3) and Washington Post[18], as well as online venues[19]. It has assumed an important role in explaining complex, data-rich problems; and uses colorful, eye-catching visuals, often structured to form narratives. Images and text regularly embellish communicative visualizations, engaging viewers and giving them clues about the type of information in the visualizations themselves. When visualizations are customized to a particular dataset or story in this way, they become *infographics*[20] (Figure 4).
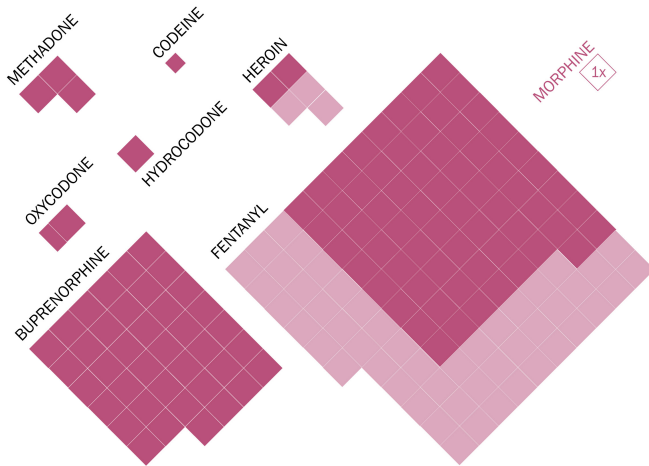

Figure 3: WaPo compares drug strengths.

Figure 4: CSPI on US sugar consumption.

In reaction, researchers have begun studying how visualization can best be used in its emerging communicative role. Kosara (in part with Mackinlay, a visualization pioneer) has provided two brief overviews of the work[21,22]. Saket et al.[25] offer a more detailed review, focusing especially on engagement and memorability.

The first step in successful communication is gaining audience attention and engagement in distracting environments. Good aesthetics are one way of getting that attention[23], and Harrison et al.[24] examined two components of aesthetics in the context of infographics: colorfulness and complexity. When they saw each infographic for less than a second, viewers preferred those that were more colorful and only moderately complex. Haroz et al.[26] studied the use of pictographs: small images used as components of visualizations. As they began looking at an array of data displays, viewers spent more time engaging with pictograph visualizations than traditional bar charts, or text-only displays.

Once viewers have attended to a visualization, a basic measure of its communicative impact is the ability of viewer to remember it. While Tufte[27] has argued that good visualizations are as simple as possible, experiments show that embellishing visualizations with imagery (as in many infographics) makes them easier to remember, without reducing understanding. Bateman et al.[28] found exactly this, with viewer recall after a few weeks better with cleverly designed embellishments. Li and Moacdieh[29] replicated this study but asked viewers to recall visualizations after less than a minute, obtaining similar results. Borkin et al.[30,31] examined memorability with a much larger and more general set of infographics, and with viewing times of only a few seconds. After a few minutes, viewers were better able to recall infographics that were colorful and included recognizable embellishments.

Understanding of visualizations is a still deeper indicator of their impact. To create higher level understanding of complex infographics, viewers must infer sequence, grouping and importance of their components. Hullman et al.[32] studied sequence, finding that given a set of visualizations related by multiple data dimensions, mapping them to a hierarchy with each level corresponding to one dimension was best understood. Bae and Watson[33] studied grouping or visual hierarchy built with multiple Gestalt cues. Viewers understood grouping most clearly when cues "reinforced" one another by being used at every hierarchical level, rather than in a "disjoint" fashion with cues communicating

only part of the hierarchy. Bylinskii et al.[34] built neural networks that predict the relative importance infographic components. Their predictions are similar to eye tracking data, but overemphasize text, and like most machine learning models, do not offer high-level explanations or guidance about how importance can be distributed during visualization design.

Finally, given accurate understanding of a visualization's message, viewers may then find that message more or less persuasive, changing attitudes, intent, and perhaps even behavior. Hullman and Diakopoulos[35] argue for this rhetorical treatment of visualization, showing how the framing methods of textual rhetoric can be adapted to visualization. Dimara et al.[37] show that the attraction effect, a cognitive bias often exploited to frame textual messages, can be exploited in visualizations as well. Pandey et al.[36] show that supporting arguments using visualizations can change attitudes more than using textual tables, particularly when viewers don't have strong pre–existing attitudes.

### Visualization for Communicating Health

While visualization researchers have begun studying communicative visualization in earnest, medical researchers have been researching it even longer, driven by pressing patient need. Visualization researchers have been largely unaware of this work, with important exceptions being Franklin et al.[39] and Ottley et al.[38], who include good surveys of it in their work.

Research on engaging patients with communicative visualizations is limited. King[40] provides a useful survey from a communication perspective, noting some evidence for preferences of bar over line graphs, and pictographs in turn over bar graphs. Also, he discusses the use of imagery to improve aesthetic appeal and perceived relevance. Lazard and Mackert[41] advocate and review evidence for the importance of aesthetics in e–health, but focus on interactive systems rather than visualization specifically.

Work on understanding communicative medical visualizations has focused on provider-patient discussion of the risks and benefits of alternative treatments, and improving patient understanding of the uncertainties involved. Fagerlin et al.[42], Hildon et al.[43], Lin and Fagerlin[44], Brust et al.[45] and Garcia-Retamero and Cokely[46] all review research on the role of visual aids in that dialog, finding that while all charts help, pictographs (Figure 5) are especially effective. Garcia-Retamero and Galesic[46] show that charts are most helpful to those with low numeracy and good graphical (visualization) literacy. Ottley et al.[38] find similar results, but add that mixing text with visuals is problematic. Tate et al.[?] used animation to communicate risk (like Franklin et al.[39]), which proved quite effective. Many visuals[49] and a few interactive systems[39,50] (Figure 6) have now been built to address this problem.
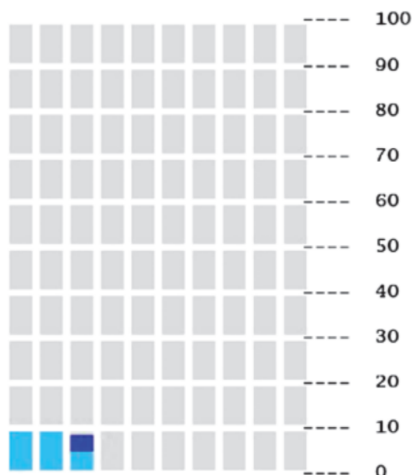
Figure 5: Risk of cataracts from taking tamoxifen.
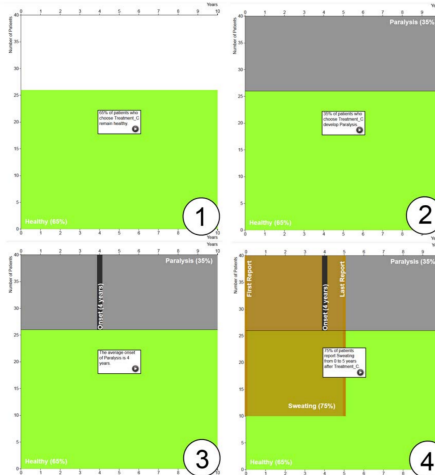
Figure 6: TreatmentExplorer paralysis and side effect risk.

Surprisingly, we could not find any research on medical visualization memorability, and work on the persuasive and

behavioral impact of medical visualizations is limited. King[40] also reviews the persuasive and behavioral impacts of medical visualization, finding advantages for pictograph depictions. Hawley et al.[51], Shirillo and Stone[52], as well as Stone et al.[53] all found that viewing pictographs led to better treatment choices.

Open Problems in Communicative Visualization for Health

As our review makes clear, we still have much to learn about using visualization for communicating health. We discuss a few open questions below:

- *Engagement* is an important first step not only when patients are with providers, but especially when they are not. These out–of–office settings are where treatment adherence and behavior change take place, and simultaneously where distractions abound. Communicative visualization has begun examining aesthetics as a means of engagement, but especially in health it should go deeper, studying more components of aesthetics including not only colorfulness and complexity but also order, familiarity, style and even interaction. There are also other components of engagement worthy of study, such as challenge, novelty and endurability.

- *Memorability* is particularly important in health, when provider–patient interactions are so brief and so few. Research on communicative visualization in general suggests that embellishments aid recall; how should they be used in the health domain? When visualizations are complex, might connecting them into narratives improve recall? How might other techniques, such as exemplification or repetition, play a role?

- *Understanding* of risk has been well studied in health visualization, but there is much more to understanding visualizations than risk. For example, chronic conditions such as MS, diabetes or obesity require regular monitoring of large, changing data streams, rather than smaller, static configurations of uncertainty. These will likely require much more complex visualizations than pictographs, with all the challenges of grouping, sequence and importance that face communicative visualization more generally.

- *Persuasion*, habit and behavior change have emerged as extremely important elements of personal health, and encompass apps like FitBit and Strava, as well as systems for smoking cessation and pain management. Most of these apps already use visualization dashboards to motivate patients. Health visualization has focused on risk. Are the visualizations and dashboards being used today motivating patients? Most patients want to improve their health, can health visualizations exploit cognitive biases to help patients overcome them?

- *Systems for provider–patient dialog* should improve to deliver understanding not only of risk, but also all the other data and decisions with which patients must cope. These systems should indeed be understandable, but they should also be engaging, memorable and persuasive. Models of communicative visualization that integrate engagement, memorability, understanding and persuasion should be developed, enabling such systems to be efficiently and effectively.

Conclusion

In its rush to digitize, the health industry has lost its way, with data dividing providers from patients and indeed from one another. Fortunately, in its emerging communicative role, visualization has the potential to reconnect patients and providers. There is much to do, but in meeting the needs of the health industry, we will help communicative visualization address society's needs more generally, including in sustainability, publishing and education.

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