Patient-centred healthcare, social media and the internet: the perfect storm?

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Patients are central to healthcare delivery, yet all too often their perspectives and input have not been considered by providers.[1][2] This is beginning to change rapidly and is having a major impact across a range of dimensions. Patients are becoming more engaged in their care and patient-centred healthcare has emerged as a major domain of quality.[3–6]

At the same time, social media in particular and the internet more broadly are widely recognised as having produced huge effects across societies. For example, few would have predicted the Arab Spring, yet it was clearly enabled by media such as Facebook and Twitter. Now these technologies are beginning to pervade the healthcare space, just as they have so many others. But what will their effects be?

These three domains—patient-centred healthcare, social media and the internet—are beginning to come together, with powerful and unpredictable consequences. We believe that they have the potential to create a major shift in how patients and healthcare organisations connect, in effect, the 'perfect storm', a phrase that has been used to describe a situation in which a rare combination of circumstances result in an event of unusual magnitude creating the potential for non-linear change.[7]

Historically, patients have paid relatively little attention to quality, safety and the experiences large groups of other patients have had, and have made choices about where to get healthcare based largely on factors like reputation, the recommendations of a friend or proximity.[8] Part of the reason for this was that information about quality or the opinions of others about their care was hard to access before the internet.

Today, patients appear to be becoming more engaged with their care in general, and one of the many results is that they are increasingly using the internet to share and rate their experiences of health care. They are also using the internet to connect with others having similar illnesses, to share experiences, and beginning to manage their illnesses by leveraging these technologies. While it is not yet clear what impact patients' use of the internet and social media will have on healthcare, they will definitely have a major effect.

Healthcare organisations have generally been laggards in this space—they need to start thinking about how they will use the internet in a variety of ways, with specific examples being leveraging the growing number of patients that are using the internet to describe their experiences of healthcare and how they can incorporate patient's feedback via the internet into the organisational quality improvement process.

PATIENT-CENTRED HEALTHCARE

Patient-centred healthcare is part of a shift in focus which has drawn increasing interest in recent years, highlighting the importance of incorporating patients' needs and perspectives into care delivery.[3] The patient's engagement with their care is now considered a key of patient-centred healthcare. One of the most important ways in which this was recognised explicitly was in the Institute of Medicine's *Crossing the Quality Chasm Report*, in which patient centeredness was considered a dimension of quality, which has helped make this a national priority.[3] Since then, higher levels of patient centeredness and patient engagement have been shown to be associated with improved clinical outcomes, health service efficiency and positive effects on health-related business metrics.[4][9–12]

Motivated further by public reports of patient experience, many healthcare

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organisations have strived to become more patient oriented and use patient surveys to assess their progress.[4] [6] [13] The 'Hospital Consumer Assessment of Healthcare Providers and Systems' (HCAHPS) is now required nationally in the USA.[14] The intent of the HCAHPS initiative was to provide a standardised survey instrument and data collection methodology for measuring patients' perspectives on hospital care. The results are available to the public which enables valid comparisons to be made across all hospitals.

INTERNET USE AND SOCIAL MEDIA

Use of the internet began to rise rapidly in the mid 1990s and since that time the internet has had an increasingly dramatic impact on culture and commerce. As the number of internet sites has rapidly multiplied and people have learned to use its advantages for a growing range of items, from shopping to finding a good restaurant in a specific area, the use of the internet for health issues has climbed.

Perhaps the major initial use of the internet for healthcare by patients was simply to seek health information. Historically, the information balance was markedly on the side of providers, but the internet clearly affected that. But in many ways, the reference information function of the internet was just the beginning. It is increasingly clear that social media represents a strong force. In addition to the rapidly increasing number of social media tools, the population using them has been growing rapidly together with access to them, and so has the potential size of their impact.

In the past, healthcare was managed mainly via interpersonal communication between the caregiver and the patient, while today, social media offers different modes of interaction. For example, Facebook has become a significant source of healthcare information, such as specific data about health conditions and healthcare facilities,[15] and blogs have become a powerful communication tool to disseminate health information and engage patients with their care. Researchers have found that, based on the data posted on Twitter, they can detect an array of types of activity, most notably disease outbreaks such as cholera and influenza,[16] [17] but more recently, data about issues like headache appearance.[18]

Last but not least, many social media websites today allow customers to describe and rate their experiences with goods and services. Consequently, people are increasingly posting reviews about their care and rating hospitals and even physicians on the internet.[19] [20] Such customer ratings have the potential to become important differentiators among healthcare organisations and providers and may have major future effects on customer behaviour and decisions. While these online patient ratings may or may not be well received by caregivers,[21] patients themselves may not consider how providers feel about these issues.

A good example of this kind of website is Yelp.com,[22] which ranks in the top 50 most popular websites in the USA and has more than 50 million monthly unique visitors and around 20 million user ratings available on its site.[23] Yelp provides online searches for local businesses and allows customers to post reviews and rate a business on a scale of 0–5. A study that was conducted by researchers at the University of California, Berkeley found that a half-star rating increase of restaurants in Yelp leads to an increase of 19 percentage points, from 30% to 49%, of restaurants' sellout rate.[24] Thus, Yelp ratings scores may change customer choice behaviour and increase business revenues. Customers have begun using the Yelp platform to rate their experiences with healthcare.

Although it is clear that the use of the internet in general and social media in particular will have major effects, it is hard to predict exactly what they will be. Already social networking has proved to be a major benefit for patients, especially those with rare conditions, to share information among themselves. However, just as today it is possible to select restaurants more effectively with Yelp, it is likely that patients will be making decisions about where to get their healthcare through such approaches—though the stakes are considerably higher in healthcare choices.

USING COMMERCIAL WEBSITE RATINGS AND SOCIAL MEDIA TO ASSESS QUALITY

Two complementary papers tackle the growing trend of internet and healthcare social media use by patients who share and rate their experiences of healthcare and the opportunity to improve quality of care based on these data. In the first, Bardach et al[25] examine the relationship between commercial website ratings of hospitals (Yelp.com) and traditional hospital performance measures (HCAHPS). In the second, Greaves et al[26] discuss the possibility of using various social media sources to detect poor performance before conventional measures of healthcare quality might reveal them.

Bardach et al[25] suggest that the ratings posted on the Yelp commercial website may be capturing experiences similar to those driving the more systematically collected HCAHPS ratings, and that improvements in these patient experience measures may be associated with improvements in patient outcomes. They found significant associations between the Yelp star scores and HCAHPS overall scores, with higher Yelp scores correlated with lower mortality rates for myocardial infarction and pneumonia and lower readmission rates for multiple conditions. The magnitude and directions of associations approximate those observed between HCAHPS and these same outcomes.[4] [11] These findings reinforce prior work by Greaves and colleagues in England. Greaves et al[27] demonstrated significant associations between unsolicited web-based patient

ratings on the National Health Service (NHS) Choices website, and traditional paper-based survey measures of patients' experiences in hospitals. These associations with clinical outcomes were at least as strong for online ratings as for traditional survey measures of patient experience. Whereas Bardach *et al* extracted patient ratings from a commercial website (Yelp), Greaves *et al* used data from the NHS Choices website,[28] a government website that encourages patients to rate and comment on healthcare organisations. These different types of websites—one commercial and one produced by a national healthcare system—may attract different users. In addition, the websites have different methods for conducting the ratings. Nevertheless, both studies produced similar findings: patients' ratings of their care via the internet correlated with several traditional metrics of quality. Moreover, other previous studies that evaluated online website ratings and traditional survey measurements of patients' experiences have also revealed associations with outcomes.[4 10 11 29]

While these studies are compelling, it is important to note that major potential biases and flaws embedded in rating systems via the internet exist and should be further investigated. People using website ratings may be more extreme (positive or negative) in their views, be younger than the general population and may vary in their health status and many other factors. Perhaps most importantly, 'gaming' may occur, in which providers or their representatives may provide favourable ratings.

In their viewpoint paper, Greaves *et al*[26] outline a novel and timely approach to collect and aggregate patients' descriptions of their experiences on the internet to detect poor clinical care and improve quality. They describe this concept as a 'cloud of patient experience'. They suggest using natural language processing and sentiment analysis to transform unstructured descriptions of patient experience on social networks, blogs, Twitter and hospital review sites into usable measures of healthcare performance. Detection of spikes of specific health-related events and disease outbreaks based on data posted on social media has been proven to be useful.[16–18] We agree with the authors that capturing and reporting these data in real time could act as an early warning of insufficient performance.

The authors suggest that such data could soon be used to assess poor clinical care and improve quality. We agree, but we think that there is still an important role for traditional surveys. The new approaches that use social media in particular just have too many potential biases, do not come from representative segments of the population and could too readily be gamed.

Finally, although both papers highlight the value for patients who use the internet and social media to share their experiences and view others, their main focus is on the value for healthcare organisations.

We believe that further in-depth studies should be conducted relating the impact of social media in general and commercial website ratings in particular on healthcare consumers and patients.

CONCLUSIONS

Patient experiences acquired via the internet and social media appear destined to become of major value to the public, to healthcare organisations and possibly also to regulatory bodies. While we believe they are unlikely to supplant more traditional patient surveys, they will certainly complement them, and should help identify poor care and outstanding care. Thus, in 10 years, the question may not be how to use such data, but how we ever lived without them.

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