

## SOUNDING BOARD

## Taking Patients' Narratives about Clinicians from Anecdote to Science

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Sometimes a picture is not worth a thousand words — or even a few sentences. So it appears for the public reporting of patients' experiences with doctors and clinics. Millions of dollars have been invested in the collection of standardized, quantitative measures of patient experience and in reporting them with the use of colorful icons that highlight the best and worst performers.<sup>1</sup> However, consumers' use of these measures remains limited because of a lack of timely exposure, doubts about the trustworthiness and relevance of metrics, and the complexity of reports and websites that incorporate multiple ratings.<sup>1-4</sup> By contrast, websites like Yelp and Angie's List, which present volunteered comments about service providers, including clinicians, have burgeoned over the past 5 years.<sup>5-7</sup> By 2013, 31% of Americans had read patients' comments online, and 21% used them when selecting a clinician — half again as many patients as report using results from standardized patient experience surveys when making a selection.<sup>8</sup> A parallel pattern is evident among clinicians. Written comments, in settings where they are currently available, are often seen by physicians as the most useful and meaningful form of patient feedback.<sup>9</sup>

The proliferation of patient comments about clinical encounters, described in their own words, was greeted skeptically by some clinicians, who worried that they were little more than a litany of grievances.<sup>10,11</sup> Because most volunteered comments (hereafter “comments”) are actually positive, these concerns were largely unfounded.<sup>6,12</sup> Our own research, however, reveals a different potential downside: comments can divert attention from other vital measures of clinician performance.<sup>13</sup>

At the same time, qualitative reports from patients about health care represent an essential missing link both for consumers seeking to understand the experience of other patients and for

physicians seeking to learn from patients to improve quality.<sup>14,15</sup> The incorporation of narrative feedback into public reporting can highlight aspects of quality that are missing from conventional surveys.<sup>12,16</sup> In addition, elicitation of narrative feedback can encourage participation in patient experience surveys by allowing consumers to report what matters most to them.<sup>17-19</sup>

Including carefully elicited patient accounts (hereafter “narratives”) as a core component of the assessment of patients' experiences would enhance the value of patients' comments. Patient narratives would be especially valuable if they were elicited and reported with the same scientific rigor already accorded to closed-ended surveys.<sup>15,20</sup> We make the case here for this approach by exploring the opportunities and challenges associated with embracing patient narratives and by considering what rigor means when it is applied to qualitative accounts.

### THE ESSENTIAL ROLE OF PATIENT NARRATIVES

Patient narratives can improve health care quality beyond what conventional report cards accomplish, by better informing consumer choice and by enhancing clinicians' understanding of encounters that are considered by their patients to be problematic. A growing number of report cards present consumers with standardized metrics of patient experience along with multiple measures of clinical performance and patient safety.<sup>8,14</sup> However, many consumers feel overwhelmed by this plethora of information.<sup>21</sup> Report designers have responded with simplified presentations,<sup>22</sup> but this does not make the actual choice process simple: consumers still must decide how to weigh different aspects of physician performance.

Consumers approach complex choices in var-

ied ways. Often, they prefer learning from the experiences of patients who are most “like them” in expectations, demographics, or health needs.<sup>3</sup> Sometimes, they rely on their emotions, basing choices on a general “feel” for clinicians.<sup>18,20,21</sup> Still other times, consumers select more deliberately, analytically combining available metrics. The balance among these approaches for any given consumer depends on context, as well as on that person’s previous health care experiences and preferred style of decision making.<sup>23</sup>

Patient narratives augment each approach. Narratives can convey what the commenter seeks in a clinician, allowing readers to focus on comments from patients whose expectations align with their own needs and preferences. Narratives often richly describe clinicians’ bedside manner, caring attitudes, professionalism, and treatment style; all of these elements are essential for assessing the “feel” of these interactions<sup>15,20,24</sup> and their emotional overtones, and yet they are missing from conventional surveys.<sup>25,26</sup>

Perhaps most importantly, narratives can act as an interpretive lens, rendering other measures meaningful for selecting among providers. Every consumer understands that a physician who is rated five stars for communication is better at explaining and listening than is one with four stars. But how much is that additional star worth if the physician in question scores worse on other valued metrics, such as timely appointments or preventive screening? Here, patient narratives play their most crucial role: helping to identify what accounts for lower ratings on certain measures of patient experience and higher ratings on others. Understanding why a provider received a particular rating can help consumers make more reasoned trade-offs, matching what they learn about various aspects of each clinician against what they value most.

Combined, these factors render narratives a potentially valuable component of informed consumer choice. Americans who have encountered comment-oriented websites before choosing a physician report that these are among the most influential sources of information.<sup>8</sup>

Narratives also can play an important role in helping clinicians understand patients’ perceptions of care. Virtually all pay-for-performance systems base incentives, in part, on patients’ survey ratings.<sup>27</sup> But for clinicians to improve their ratings, they need to understand why pa-

tients have withheld more favorable scores.<sup>9,15</sup> Patient narratives offer the necessary detail. Of course, patients cannot always discern precisely what gave rise to problems and may misidentify the source of their dissatisfaction. Nonetheless, narratives offer clues that clinicians can interpret much more constructively than just a standardized survey score.<sup>15</sup>

Reading patients’ comments can also help clinicians identify problems masked by a generally satisfied clientele. As many as a quarter of patients who top-rated their provider on closed-ended questions nonetheless describe one or more serious problems with care in their comments.<sup>28,29</sup> Similarly, narratives can facilitate the process of pinpointing and addressing systemic causes of quality shortfalls by allowing physician groups to identify when multiple patients treated by different clinicians all report similar problems.<sup>30-33</sup>

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#### REDUCING THREATS POSED BY ANECDOTAL COMMENTARY

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Although clinicians worry that only aggrieved patients leave comments, in practice 65 to 90% of patient accounts are positive.<sup>7,12,28,34,35</sup> However, the growing prevalence of comments raises different concerns: that narratives will interfere with consumers’ use of other metrics and undermine clinicians’ confidence in patient feedback.

The threat for consumers takes two forms. First, the burgeoning number of websites populated largely or exclusively by patient comments may crowd out sites with more robust quality metrics.<sup>4,8</sup> The websites found most easily in Web searches all include patient comments, but only 40% present other quality metrics.<sup>4</sup> Comment-only sites are typically commercial enterprises that are marketing themselves aggressively.<sup>4,8</sup> When consumers truncate their search for information about clinicians after encountering only sites with generous marketing budgets, they may never even be exposed to many potentially valuable quality metrics.<sup>36</sup>

When consumers do find their way to websites containing more comprehensive performance metrics, the greater emotional accessibility of narratives may produce a second problem: a disproportionate focus on comments relative to other measures.<sup>37</sup> Our research shows that although consumers spend more time and interact more on websites with narratives, they de-

vote substantially less attention to quantitative ratings on those sites, as compared with sites without comments. They also spend less time drilling down to the data behind the ratings and home in so quickly on subsets of clinicians that they miss other potentially preferable options.<sup>13</sup> To be clear, the problem is not that consumers prefer narratives over star ratings; it is that when comments are present, consumers weigh their options less carefully, failing to investigate the components of star ratings to learn what they convey. Further, some consumers who report valuing star-rated aspects of care nonetheless disregard those ratings when choosing a clinician on a site that includes comments.<sup>13</sup>

Conversely, the anecdotal origins of existing comments may lead some clinicians to discount their potential value. Most existing websites post comments submitted from any source, with no assurance that they come from real, recent patients. Clinicians' legitimate concerns about accuracy and representativeness may discourage them from using comments for improving clinical practice. Deriving meaning from narratives demands time and careful analysis — time arguably not well spent for fragmentary, biased, or unrepresentative comments.<sup>9,30</sup>

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A CONSTRUCTIVE RESPONSE:  
TOWARD A RIGOROUS SCIENCE  
FOR PATIENT NARRATIVES

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Without active policy intervention, the pernicious influences of comments may outweigh the positive. Commercial websites have marketing resources that far exceed outreach budgets at nonprofit and government-run public reporting websites.<sup>4</sup> If public reporting sites try to match the appeal of commercial ones by incorporating open-ended patient feedback, they may inadvertently distract users from other valuable metrics of clinician performance. One way to address the diversionary threats posed by comments — and revitalize the positive potential of hearing from patients in their own words — is to hold narrative data to the same standard of scientific rigor that is already applied to conventional patient experience surveys.

What sort of “rigor” applies to the elicitation and reporting of patient narratives? Most importantly, there should be some assurance that narratives are representative of patient experience.

This requires active elicitation of feedback; volunteered comments substantially underreport negative encounters and the experiences of socially isolated or less educated patients.<sup>38,39</sup> Representativeness, in the form of widespread participation, might best be achieved by integrating open-ended questions into existing standardized surveys, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) instruments. But representativeness also depends on eliciting full narratives from patients who are less comfortable portraying their experiences, including, perhaps, deployment of phone-based protocols to address disparities in literacy.

Rigor also requires elicitation protocols that are tested to ensure that they induce fulsome commentary from patients' varied experiences and health statuses. “Fulsome” in this context means deriving not only positive and negative experiences but also narratives that describe all aspects of care that concern consumers when selecting clinicians.<sup>12</sup> Effective elicitation also induces a coherent description of what happened from the patient's perspective and why it mattered, as well as details that allow readers to discern whether they identify with the narrator in terms of health needs, expectations for care, and preferences for autonomy.<sup>33,40</sup> This will not be accomplished by simply inserting open-ended questions asking whether patients have “anything else to add.” Both the wording and the sequencing of questions are important in encouraging detailed and coherent narratives. A number of existing, validated techniques for assessing narratives can be applied to ensure that patient accounts are both complete and meaningful.<sup>41,42</sup>

A systematic and careful approach to the reporting of patient narratives on websites would improve their value. Guidelines would need to be developed to decide what is considered a legitimate source for feedback (e.g., are caregivers acceptable reporters?), to decide whether and how they should be edited, and to clarify how long they should remain posted. Additional research is required to define how to report narratives so that they will be readily comprehended by consumers (e.g., presented in their entirety or edited to focus on particular aspects of care?) and most effectively integrated with quantitative metrics. For example, narratives could be “tagged” with topical labels that match ratings from conventional surveys, tagged with a patient's health

conditions so that users could learn from patients with similar treatment needs, or tagged with ratings that allow sorting on the basis of emotional (negative or positive) valence. Finally, rigorous testing of reporting methods would be necessary to ensure their usability and interpretability by those who are less health literate or less experienced with health care and to ensure their usefulness to clinicians in quality-improvement initiatives.

#### IMMEDIATE AND EXTENDED IMPLICATIONS

For decades, the United States led in research and public sector investment into conventional patient experience surveys.<sup>15,43</sup> However, it now lags behind when it comes to using patient narratives to improve care. Rigorous elicitation and reporting of patient narratives would require a concerted plan of investment in both research and implementation. The Agency for Healthcare Research and Quality accelerated this work several years ago with its Building the Science of Public Reporting program, although fully developed elicitation protocols that are applicable to all clinical settings will require several more years of development. The incorporation of narrative accounts into public reporting would require more resources than just opening up websites to patient anecdotes. When patient comments were incorporated into the U.K. National Health Service (NHS) Choices website, a bevy of nonprofit organizations curated the comments before they were posted online.<sup>31</sup> A similar infrastructure would be required in this country, but its capacity could be developed incrementally over time.

Rigorously elicited narratives will never entirely displace volunteered patient comments — nor should they. If patients have severe problems with access or quality, they should and will voice their concerns immediately, using whatever platform for giving voice they deem appropriate. But these volunteered grievances do not provide an accurate representation of patient experiences or health system performance.<sup>38,44</sup>

Beyond the immediate benefits of the careful elicitation and reporting of narratives outlined above, patient commentaries may have deeper transformative potential. In the longer run, patient narratives on public websites might encourage providers to post replies — as hospitals are

beginning to demonstrate on the NHS website<sup>40</sup> — allowing consumers to identify the most responsive clinicians.<sup>33</sup> Public descriptions of how diverse patients addressed problems might also enlarge other consumers' ideas about patient empowerment.<sup>45</sup> Further, an accumulated, accessible bank of patient narratives might help policymakers detect systemic shortfalls in health system performance. The potential benefits of this innovation have already been documented in the United Kingdom and New Zealand, which have committed substantial resources to identifying patterns in qualitative patient comments.<sup>33,38</sup>

A rigorous approach to the elicitation and public reporting of patient narratives could help consumers make more informed choices and better encourage clinicians to react constructively when problems arise. As TripAdvisor, Amazon, and other sites with consumer reviews exert increasing influence over consumer choices, the effect of patients' narratives about clinicians is bound to grow as well.<sup>46</sup> This growing salience will undoubtedly be most visible in the United States, where consumer empowerment is a central motif for improving health system performance. But it will also emerge globally, as policymakers in many countries seek health systems that are more responsive to patient experience.<sup>31,44</sup> A consistently elicited stock of patient narratives could yield more nuanced cross-national comparisons, revealing new lessons for improving health care around the world. Clearer guidelines and strategic investments today would help ensure that these influential narratives reflect representative, fulsome, coherent accounts of patient experience.

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