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The Importance Of Integrating Narrative Into Health Care Decision Making

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ABSTRACT **When making health care decisions, patients and consumers use data but also gather stories from family and friends. When advising patients, clinicians consult the medical evidence but also use professional judgment. These stories and judgments, as well as other forms of narrative, shape decision making but remain poorly understood. Furthermore, qualitative research methods to examine narrative are rarely included in health science research. We illustrate how narratives shape decision making and explain why it is difficult but necessary to integrate qualitative research on narrative into the health sciences. We draw on social-scientific insights on rigorous qualitative research and our ongoing studies of decision making by patients with cancer, and we describe new tools and approaches that link qualitative research findings with the predominantly quantitative health science scholarship. Finally, we highlight the benefits of more fully integrating qualitative research and narrative analysis into the medical evidence base and into evidence-based medical practice.**

In a January 2001 Narrative Matters essay in *Health Affairs*, John McDonough, a former state legislator, reflected on how stories affect policy making. Storytelling will always be part of the policy process, he wrote, but we can seek to improve policy makers' ability to interpret the stories they hear.[1] McDonough's perspective is instructive not only for the field of health policy but for health decision making generally. Anthropologists, linguists, and neuroscientists tell us that human beings are storytellers.[2] People think, communicate, and make decisions through stories and narrative, which makes it imperative that researchers, health practitioners, and policy makers learn how to interpret narrative more skillfully.

In this article we define *narrative* as a spoken or written account of real-life—instead of fictional or hypothetical—events, told from the viewpoint of someone who experienced them. Patients mine narratives from family members, friends, and the media when making health decisions in exam rooms, hospital rooms, and living rooms.[3,4] In policy, it is said that a well-timed narrative anecdote "can vaporize a mountain of data and careful policy analysis."[1(p209)] Clinicians use their professional judgment to guide patients' decisions—and that judgment draws on both medical research and a narrative about how a particular patient fits in with other patients they have treated or heard about.[5] Through multiple channels such as patient stories, policy anecdotes, and professional judgments, narrative shapes our approach to health decisions.

Yet narrative is often excluded from the medical evidence base. It may appear in sections of publications, such as the Narrative Matters essays in *Health Affairs*, but rarely does it form the heart of an original research report in a medical journal.[6] The health sciences have limited techniques for rigorous narrative analysis, and clinicians and patients have few tools to use in addressing the narrative dynamics of decision making. Patients and clinicians, as well as policy makers, could benefit from increasing their skill at interpreting stories but largely lack the means for doing so.

In this article we illustrate how narrative influences health decisions by patients and clinicians, and we discuss the need to improve how we use narrative as evidence. We examine why narrative insights remain overlooked despite a growing appreciation for qualitative methods.[7,8] We describe tools and approaches to bridge the gap between qualitative inquiry and health science, and we discuss how these tools could support rigorous qualitative research that integrated narrative data and insights into medical evidence.

How Narrative Matters

In health decision making, narrative can trump the evidence base for the following reasons, among others: Medical evidence may not measure patient-centered outcomes, may not include diverse populations, or may overlook issues related to chronic illnesses or comorbidities.[9] For patients represented in the evidence base, quantitative data can be confusing or seem irrelevant in the midst of decision making. In contrast, accounts of illnesses and treatments, cautionary tales, previous experiences, and common sense may seem to provide compelling and actionable information.[10] Such narratives may not constitute a reliable basis for sound health care decision making on their own.[4] But, handled appropriately, they can be helpful to patients and clinicians.

To illustrate the use of narrative in decision making, we use four examples—two from the authors' published studies and two from Narrative Matters essays in *Health Affairs*. The first two examples show patients invoking narrative, while the final two examples show how clinicians draw on their professional experiences in making clinical judgments. The four examples illustrate the value of narrative evidence and the challenges of integrating narrative and conventional medical and scientific evidence.

Policy makers also use narrative in decision making, but in this article we focus on patients and clinicians who share the challenge of incorporating narrative into decisions about what is best for an individual's health—as opposed to the health of a population or constituency.

PATIENTS' USE OF NARRATIVES Rebecca was fifty-five years old when she was diagnosed with ductal carcinoma in situ (DCIS, a noninvasive breast cancer) and joined a longitudinal study of the experiences and treatment decision making of patients with breast cancer conducted by two of the authors (Katharine A. Rendle and Meghan Halley) and colleagues.[11] Despite strong recommendations from her surgeon to undergo a less aggressive procedure, Rebecca opted for bilateral mastectomy. In an ethnographic interview, she described how a conversation with a breast cancer survivor had informed her decision: "Like me, [this survivor] had had children and she…said, 'You know, [my breasts] were getting a bit saggy. I had breastfed a lot…and if I have one breast that's getting old and saggy, and one silicone…I feel [like] a victim. I feel like I've had an illness whereas all these California women who are investing in their bodies and having silicone implants, they are having this very similar kind of surgery [to mastectomy].' That made me laugh and sort of ticked into how I feel and I sort of thought, yeah I totally get that…. And actually if insurance is gonna pay for this, you know, hey, I'm gonna come out of this ahead and I'm gonna choose the size. And she said to me, 'You know what? I can even go braless these days.'… And I was just thinking, oh, my God, that would be exciting."[11(p1256)]

Through the survivor's narrative, Rebecca found a way to understand her own diagnosis of DCIS as an opportunity to empower herself. From the perspective of clinical evidence, mastectomy was unnecessarily aggressive, but from a personal perspective, the procedure aligned with Rebecca's feelings about her identity, sexuality, and sense of empowerment.

Her interview shows how she arrived at this understanding and provides novel insights into decision making that quantitative evidence from medical records or patient surveys cannot replicate. Even surveys that gather patient-centered information provide only limited ways to represent a woman's experience.[12] In contrast, narrative data can lead to new and unexpected insights for researchers and clinicians, such as about how a treatment decision may reflect issues of body image that emerge in the context of social support.

In our second example, Jessie Gruman, who was founder and president of the Center for Advancing Health until her death in 2014, described her search for a surgeon to treat her stomach cancer in a Narrative Matters essay.[13] In the excerpt below, she illustrated how word-of-mouth recommendations are at times more meaningful to patients than quantitative quality data when deciding where to seek care:

"My first urgent task was to find the right doctor in New York City, a center of the tertiary care universe, to remove a stomach tumor….

"I searched online but found that comparative quality information on surgeons specializing in stomach cancer was virtually nonexistent. Commercial physician ratings are based on academic credentials, board certifications, and peer ratings rather than outcomes or credible patient reviews.

"I quickly realized that even with today's new resources to help find good doctors, the most reliable way to distinguish the merely qualified doctor from the expert one remains recommendations from people who know people, doctors who know doctors. And so began a week of countless phone calls and e-mails."[13(pp427–8)]

Gruman acted on information from friends and friends of friends while viewing publicly available clinician ratings with skepticism. It took a savvy patient to recognize that the public ratings were based on academic credentials and board ratings, which do not necessarily provide reliable evidence about patient outcomes. And it speaks to the power of narrative that a patient was willing to place her trust in the anecdotes that she gathered personally.

CLINICIANS' USE OF NARRATIVES Narrative also shapes how clinicians guide patient decisions. The medical evidence base is a crucial resource for treatment recommendation, but clinicians also draw on their professional judgment to assess the evidence in light of a patient's situation. They guide patients toward options that seem sensible given their professional understanding of the patients' needs and desires. In the process, clinicians draw on narratives of past patients and narratives shared by colleagues and teachers over the years.

In the excerpt below, from our study of decision making by patients with cancer, Christopher Koenig and colleagues describe an exam room discussion in which a patient asks his oncologist about the changes in diet he is contemplating.[14] Their interaction illustrates the dynamic relationships between professional experience, clinical judgment, and medical evidence: "Mr. Lane recounts that he and his spouse have been doing a lot of diet changes, such as cutting out meat and dairy and eating brown rice, and some homeopathic stuff. Mr. Lane finally asks, 'Will that make any difference do you think?' Dr. Rivera replies, 'With some very strict diets the PSA [prostate-specific antigen] increases less quickly, but these diets are very hard to maintain. They don't affect just individuals, but whole families, which can be very disruptive. There's also a big danger with adherence—when people don't feel like they can maintain these diets, they begin to feel like they are complicit in making their cancer grow. What I don't want is for you to feel guilty or feel like you've failed to control the cancer. What I can say is that a general "heart smart" healthy diet will go a long way without being too disruptive.' Dr. Rivera shifts topics by saying that PSAs typically increase for these types of tumors, so you should have a CAT scan and a bone scan after 12 weeks."[14(p861)]

In parts of this conversation, the physician's recommendations seem grounded in conventional medical evidence, such as the benefits of a "heart smart" diet and the need for computed tomography (CT) scans (also called CAT scans, for computerized axial tomography). At other times, his recommendations reflect clinical judgment honed during a career caring for patients with cancer. The physician appears to draw on this experience-based narrative when he cautions his patient against attempting a major dietary change.

His concerns appear genuine, he presents them sensitively, and they reflect his shared history with this patient. However, clinical judgment remains subjective and idiosyncratic, a reflection of the fact that it develops organically instead of through the validated procedures of the conventional medical evidence base. Recommendations based on clinicians' judgment—presented as narrative—can improve patients' experiences, but they can also miss the target because it can be difficult to fully appreciate patients' core goals, values, and preferences. The following example illustrates this clearly.

In a Narrative Matters essay, Diane Meier, a palliative care physician, discusses her experiences caring for a patient called "Jenny" in the essay, whose oncologist aggressively treated her terminal lung cancer during multiple rounds of chemotherapy.[15] After the oncologist recommends another course of aggressive therapy, Meier decides to ask him why:

"'Jenny was in today, and she mentioned that you had suggested intrathecal chemo for her brain metastases,' I said. 'I told her I'd call to find out what you anticipated from this approach, since this is outside my expertise. What are you hoping we can accomplish with this treatment?'

"After a brief pause, he spoke. 'It won't help her.'

"I struggled for a response. 'Would you want me to encourage her to go ahead with it anyway?' I asked, finally.

"After another pause, this one longer and more awkward than the last, he said, 'I don't want Jenny to think I'm abandoning her.'…

"His comment struck me.…

"It seemed that the only way Jenny's oncologist knew to express his care and commitment for her was to order tests and interventions. He felt that to stop doing this was akin to abandoning her. His words transformed my understanding of what I've viewed as inexplicable behavior in the face of progressive and terminal illness."[15(p896–7)]

This conversation helped Meier understand what could be viewed as overtreatment on the part of the oncologist. The oncologist's clinical judgment—to recommend treatment that would have no clinical benefit for his patient—was based not on medical evidence but on a narrative developed from his professional experiences and his observations and assumptions about Jenny's situation. Though the oncologist was well-intentioned, this example nevertheless illustrates how difficult it can be to construct an accurate narrative of a patient's illness experience and the potential risks of recommending treatment options based on a misunderstanding of a patient's core values and goals.

Reconciling Narrative And Health Science Data

These examples show how narrative can shape patients' and clinicians' decision making. As noted above, however, narrative's role in decision making remains underexplored in health science and policy research. Three key reasons account for this situation. First, qualitative studies often do not gather data from representative populations, and thus their results may not be generalizable. Second, to maintain confidentiality and because the data are voluminous, investigators rarely share qualitative data sets, which makes it difficult to combine or compare findings from different qualitative studies. Finally, these limitations on generalizability and data sharing can make it difficult to translate qualitative findings into practical strategies for health improvement.

Considering these challenges, some research methodologists have argued that narrative analysis should remain separate and distinct from scientific inquiry.[16] In studies of health, this approach would have the effect of maintaining the status quo, in which narrative health data often appear in specialized journals whose readers are drawn from the medical humanities or social sciences but not the health sciences.

However, other methodologists have called for efforts to bridge the gap between narrative and scientific evidence.[17] Given narrative's role in decision making and decision research, continued investment in efforts to bridge that gap appears reasonable.[4] New methodological tools must be developed that balance narrative richness, scientific rigor, and practical utility. Such tools could advance scholarly understanding of decision making and improve how patients and clinicians make health care decisions in everyday life. Below we describe how, with support from the Patient-Centered Outcomes Research Institute (PCORI), we are exploring ways to address the challenge of integrating qualitative data into medical evidence and practice.

Integrating Narrative Into Decision Making: Tools And Approaches

The stories of Rebecca and Mr. Lane are taken from studies our research group is conducting on treatment decisions by patients with cancer. One of our studies focuses on cancer patients' decisions to join (or not join) an early-phase clinical trial. Using ethnographic interviews and observation, we systematically collected narratives from approximately a hundred patients with advanced cancer. As we examined their decisions, it seemed likely that their narratives—of illness trajectories, family discussions, and clinical interactions—held insights beyond those available from standard qualitative analysis.

We sought a new way to analyze these data and drew inspiration from the bench sciences, where molecular biologists use microarray technology to decipher gene expression patterns. Genetic microarrays analyze DNA and display the resulting data using a heat map—a graphical representation in which color, hue, and intensity represent the data. For example, a genetic microarray can show how thousands of genes are expressed in hundreds of DNA samples. Genes that are highly overexpressed will appear as areas of bright green, while underexpressed genes will show up as red areas. Microarray analysis of DNA from breast cells shows distinct patterns of green and red in normal compared to cancerous cells.[18] Interestingly, the heat maps reveal that each different type of cancer has a distinct pattern of genetic expression.

We wondered if a tool similar to the genetic microarray could graphically represent the experiences of patients with cancer. Such a narrative heat map might include patients' demographic characteristics, clinical conditions, decisions, and outcomes. A map that showed many patients simultaneously could allow researchers, clinicians, patients, and caregivers to more easily understand how their own experience compares to the cancer journeys of others.

With support from PCORI, we are currently building this tool, which we call an ethnographic array, or "ethnoarray."[19] We developed the ethnoarray to better understand how contextual, clinical, and personal factors as well as family and clinical interactions shape patients' decisions to seek enrollment in a cancer clinical trial.[20] Our hope is that it can identify patterns of decision making that present quantitative and qualitative analyses cannot detect.

Decision-making pathways, such as those revealed in the ethnoarray, may also help address the health decision challenge of organizing information. Patients facing serious health decisions often receive new news. Clinicians, family members, friends, the Internet, and patients' own bodies constitute an endless source of test results, advice and recommendations, and symptoms and side effects. The information rarely speaks for itself. Instead, patients (together with their providers) must decide which facts to consider and which to ignore, and how to make decisions accordingly.

In situations such as these, patients and clinicians may need help interpreting information and organizing it in order of importance. A narrative story line can help by supplying a sense of structure, plot, and context and a timeline that helps patients and providers arrive at decisions that feel sensible, informed, and transparent.[4] Narrative story lines don't tell patients or clinicians what to do so much as remind them of the pathways and choices they face.

Currently, story lines arise idiosyncratically from patients' histories, networks, and clinical interactions. Qualitative analysis can provide evidence-based story lines. Building on a thematic analysis of patient interviews, we developed a short video that illustrated a common story line we heard during interviews with patients who had stage IV cancer. The video reminds similar patients that one important choice they face is whether to pursue symptom management, curative therapy, a clinical trial, or a combination. It illustrates each pathway with an emphasis on the practical consequences of each choice.

In pilot tests, patients reported that the video helped remind them of big-picture issues that might otherwise have gotten lost amid the countless everyday issues involved in living with a complex illness. Both the ethnoarray and the video for patients with advanced cancer suggest how curated qualitative data can be a valuable source of evidence to guide health decisions.

Recommendations

Stories and narratives, collected and analyzed systematically, can yield qualitative evidence to improve and guide decision making. We echo McDonough's call to embrace insights and perspectives gleaned from stories and narrative, and we note that the social sciences have a rich tradition of examining what narrative means and how to distinguish data from anecdote. McDonough found that a simple question—How do you know that?—could help separate reasonable anecdotes from irresponsible storytelling. But turning stories into narratives for use by patients, scientists, clinicians, and policy makers requires more, including methodological innovation and new data infrastructure.

In terms of methodology, no need is more urgent than establishing guidelines for systematic qualitative research. Multiple attempts have been made to establish such guidelines, but qualitative scholars do not agree on which guidelines are appropriate and helpful.[21,22] It may be sensible to recognize that there are multiple forms and applications of qualitative analysis and that different standards may be appropriate for single-case exploratory studies and for multiple-case comparative studies.

There is no dominant funder of qualitative research to champion the establishment of such guidelines, however. The National Science Foundation, National Institutes of Health, and Robert Wood Johnson Foundation have published guidance on qualitative methods. But these guidelines have not proliferated widely, and no research funder, professional society, or publisher has sought to become the arbiter of qualitative research. As narrative analysis continues to augment health science and practice, it is possible that an institutional champion such as PCORI could help establish such guidelines.

Data infrastructure to support qualitative research is a second critical priority. Capacity is not the issue, as qualitative data sets are small compared to the administrative and biomedical data sets already in routine use. But sharing rich, context-dependent qualitative data raises ethical and legal issues.

Investigators have yet to devise methods that adequately shield the confidentiality of research subjects in a large qualitative health data set. In quantitative studies, researchers protect confidentiality by concealing personally identifiable information in raw data, by sharing only aggregated data, or both. For small qualitative studies, researchers conceal details about subjects and sites in published reports and do not share large amounts of raw data. Neither concealment nor aggregation is a viable strategy for protecting confidentiality in large qualitative data sets, however. Aggregation can protect confidentiality, but it destroys the richness that makes qualitative data valuable. Similarly, masking identities completely would conceal so much contextual detail that the data would be uninformative.

A qualitative research infrastructure thus requires innovative social engineering. The bench sciences may again offer models worth emulating, such as the National Institutes of Health's policy on sharing genomic data.[23] Such efforts have established a research community whose members are able to share sensitive genetic data using honest brokers, legal arrangements to ensure that participating institutions are exposed only to manageable risk, and reliable punishments to discourage misuse of the data.

Conclusion

We are at the beginning of what promises to be a long and uncertain process of trying to integrate narrative data into health science research and health care decision making. A successful outcome of this process is far from guaranteed, but the payoff could be substantial. As Glyn Elwyn and colleagues note, "Although numbers are powerful, stories trump numbers, and relationships trump stories."[10(p707)] Developing new qualitative research tools could help ensure that patients, clinicians, researchers, and policy makers properly account for and benefit from the power of stories in health decision making. ■

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