

## Stories That Work

Anjali Jain, MD

From The Lewin Group, Falls Church, Va

The author declares that she has no conflict of interest.

Address correspondence to Anjali Jain, MD, The Lewin Group, 3130 Fairview Park Dr, Suite 800, Falls Church, VA 22042 (e-mail: [anjali.gj@gmail.com](mailto:anjali.gj@gmail.com)).

ACADEMIC PEDIATRICS 2013;13:287–289

I HAVE NEVER met Natoma Canfield, but I am unlikely to forget her story. Natoma is a woman with cancer who had dutifully paid her health insurance premiums over the years she was healthy but then could no longer afford them when she became sick, and they increased. Ultimately, she lost coverage. Natoma's story was the one President Barack Obama relayed on the historic day last summer that the Patient Protection and Affordable Care Act was upheld by the Supreme Court. Her experience encapsulated the health care debate at a time when all the facts—the pros, the cons—were questioned by the other side. But we couldn't argue with the truth of her story.

Stories are powerful. Compared to studies that are summations of large numbers of events—or many stories made bland by their blending—stories, with sample sizes of only one, penetrate and resonate. They can lodge in memory in ways that cannot be easily erased. They can diminish the importance of facts, whether or not they agree with them. Increasing recognition of this power has resulted in the appearance of stories and narrative forms in many traditional biomedical journals, including this journal as well as the *New England Journal of Medicine*, *JAMA*, *Health Affairs*, among others. The potency of the story in the health care debate is breathtaking.

Meisel and Karlawish in 2011 spoke of the need for both evidence and narrative, rather than having to choose between them.<sup>1</sup> They asserted that both forms of dissemination have unique strengths and weaknesses that can be complementary, and that the sum of the two can be more effective than either alone. Evidence and narrative are not necessarily equal, however. In contrast to narrative, scientific evidence is held to standards of rigor. Although peer review continues to be an imperfect system, studies are scrutinized on multiple occasions: by funders, institutional review boards, editors and peer reviewers, and eventually the lay press and the public. Reviewers who are not directly involved with the studies assess them for truth or validity, for fairness and consideration to the individuals involved, and finally for the usefulness of the knowledge gained.

Stories lack such controls. Currently there are no established ideals or standards to which narratives must adhere before entering the public or policy realm. Indeed, it can

often be the undisciplined tale that is the most free to take off and to roar. An oft-quoted example is the curious strength of the narrative linking vaccines and autism. Although its survival is at least partially related to its initial purported scientific validity, this story—believed by most researchers to be false—continues to defy the many layers of examination and oversight that have since been imposed on every aspect of the science. Indeed, this story changed behaviors on an international scale, and continues to do so; concern about autism is one of the most cited reasons among parents who refuse vaccines.<sup>2</sup> This story has perhaps gathered force over time, now contributing to a different and powerful narrative: one that suggests that the scientific community and the government purposefully withhold evidence from individuals if it runs counter to the interests of powerful groups.

Despite being armed with substantial evidence, the United States Preventive Services Task Force (USPSTF) continues to struggle against this kind of narrative. The USPSTF recently issued guidelines regarding prostate-specific antigen (PSA), suggesting that this screening test is less useful than previously believed. Although the evidence behind these guidelines is not terribly controversial, when the guidelines were announced, the airwaves rang with stories from individuals who believed their lives were saved by this screening test. These stories were held up as if to balance, even outweigh, the evidence. When weighed against the stories of real people, with names and faces, science often finds itself cowering in the corner, rendered meaningless and insensitive.

There are, on the other hand, many examples of stories that need to be told, that say something better or more meaningfully than data alone. Such stories, like Natoma's, might convey a message that is endorsed by evidence but is better communicated at an individual level. Or there might be tales that describe the nuances of an event, thereby pointing perfectly and poignantly to a problem that needs to be addressed, for which evidence may not yet be gathered or recognized. A single story can also be an early sign of a problem and a catalyst toward better science and policy. The story of 12-year-old Deamonte Driver's death from a tooth abscess in 2007, for example, exposed the difficulty of securing dental care for poor children

and led to policies improving oral health care coverage for children overall.

Considering both the potential benefits and harms of stories in health and health care, is there a way to sort them, a way to decide which should be released widely and which should not? Are there thresholds we can use to identify the stories that serve the public and move, rather than impede, knowledge? Because the state of science itself is ever-changing, and because new truths are often unpopular or uncomfortable, how do we air narratives responsibly, yet without denying an important voice? What are the stories that work?

As the editor of the narrative essay section in this journal called "In the Moment," after having reviewed hundreds of submissions over the 6 years of this section, I developed an informal checklist that might serve as a set of standards for responsibly publishing stories in health and medicine. I describe it below.

Whose story is it? Perhaps not surprising, given the readership of medical journals, many of the narratives published in our journal as well as in others are accounts by physicians about patient experiences. They can be about events that seem unusual and original, but also larger somehow—the teachable moments of medicine. Just as we as health care providers take ownership of our patients' health care—in a beneficent way—we can easily fall into thinking that our patients' stories also belong to us, sometimes more than to the patients themselves. It is common, for example, for authors to submit stories for publication assuming they need not ask permission of the patient who is the subject of the story. Although this practice was probably thought of as harmless in the past, medicine is slowly recognizing that the health and care of patients belongs foremost to the patients themselves. For other people's stories, which have not been explicitly turned over to our custody, our ownership is even more in question. Patients share their stories trusting the details will serve their health and interests. We cannot assume the privilege is ours to pass on to others.

Putting a story into print, and one that can have a life far beyond its initial publication, requires a sense of responsibility to the individuals involved, named or otherwise. So I ask authors to seek permission to publish from all the significant characters in the story and to produce permission in writing. I also ask authors to share the accounts with the characters described whenever possible, if they can be located or contacted. It is ideal if real names can be used. But if not, names and other potentially identifying details that do not change the thrust of the story can be altered. In the final version, the scope of both accuracies and inaccuracies are presented with transparency.

Is it honest? In general, I look for stories that are true or honest, both literally and in spirit. Occasionally, in "In the Moment," as in other narrative sections, we publish fictional stories (these are declared as such outright), where characters are a composite of several individuals, or where the account is a quasi-fictionalized account of a real event, where the details might be recognizable or risky for the individuals involved. However, we receive and publish

fiction rarely despite its ability to sometimes tell truths that may not be possible when real lives and reputations are concerned. When I receive nonfiction, I am rarely able to confirm the facts of a story—that the events took place as reported—so I instead try to discern whether a story rings true. The truth is usually messy or incompletely resolved, so stories that end too tidily can strike a false or unreal note. Perhaps even more important is the ability to recognize a factually accurate anecdote that is not telling a larger truth beyond the peculiarities of a single situation. A story that is thus a fluke, a one-off, seems less important or responsible to convey.

Is it fair—or, better, generous? Many of the important stories in health care point to flaws in our health care system or within the players involved—patients, professionals, and others. Thus, a slight turn may convert a meaningful narrative into a lament, a one-sided tale of woe. These kinds of stories can potentially serve a different purpose by offering a fresh perspective or opinion, more in line with editorials or commentaries rather than following a narrative arc. But for narrative pieces, I ask that authors take great care that all the characters in the story are treated fairly and, whenever possible, generously. The story works if the reader can understand the motivations of all who are involved, even if only to a limited degree. All the characters must come across as human, neither all good nor all bad. The doctor who made the wrong diagnosis, the patient that did not show up, the administrator who focused on the wrong priorities, the policy maker with a personal interest—each of these represents values, priorities, and motivations that come into conflict, that are different but not necessarily better or worse.

Is it well written, does it flow? What makes health narratives well written can be elusive, but a few guidelines have helped me to help authors tell their stories more clearly. I look for stories to have a beginning, a middle, and an end. In the beginning, the details of the scene are described, so readers can picture the room or the scene in their minds and wait alongside the writer or narrator for events to unfold. In the middle, something happens—an event, a conversation, a conflict, a stimulus. In the end, the characters in the story are changed somehow—typically the main character, and in health narratives, most often the narrator. As the stories are usually first-person accounts, it is often the narrator who learns something about him- or herself and is transformed in some way as a result. It is the narrator who describes what happened and why it is important. In the most effective stories—the ones that stay with us—the protagonist shows the strengths and talents of the hero but also, and more notably, humility and vulnerability, and thus an ability to be affected by the interactions and circumstances of the story. Indeed, it is that very uncovering the reader most relates to and identifies with. Then the reader is there, part of the story—hooked, engaged, even moved.

In health care, the important stories are often the sad ones, those without much of a chance for happy endings. They depict seemingly small glitches in systems and

behaviors that end up meaning something. Or they are about something that goes wrong, something that accelerates the life of the hero toward his or her inevitable outcome, thus reminding us of our own mortality, whether near or far. But tragedies can also be redeemed, and perhaps—especially in health care—they need to be. Perhaps the only way to save those who weren't saved but could have been—should have been—is to tell their stories. Although the human instinct for stories has been

well discussed over the ages and by scholars in every field,<sup>3</sup> it is a good yarn, one worth telling again.

### REFERENCES

1. Meisel ZF, Karlawish J. Narrative vs evidence-based medicine—and, not or. *JAMA*. 2011;306:2022–2023.
2. Freed GL, Clark SJ, Butchart AT, et al. Parental vaccine safety concerns in 2009. *Pediatrics*. 2010;125:654–659.
3. Fisher WR. Narration as a human communication paradigm: the case of public moral argument. *Commun Monogr*. 1984;52:347–367.