

The story behind the science: Physicians point to patient narratives to bolster the case of evidence-based medicine

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Doctors should consider the use of narrative -- in the form of patient stories and testimonials -- as a powerful tool for translating and communicating evidence-based policies to the public to buoy buy-in on important health issues such as cancer screenings and vaccination mandates, according to two physicians from the Perelman School of Medicine at the University of Pennsylvania writing this week in *JAMA*. They suggest two strategies: The use of so-called "counternarratives," which can play a role in neutralizing personal stories -- often promoted by celebrities via the news media -- that support disproven theories, and narratives about the process of scientific study and discovery, to unmask the often hidden work of researchers and guidelines committees.

The role of narrative in [medicine](#) rose up this fall, when both Rudy Giuliani and Joe Torre spoke out against the new U.S. Preventive Services Task Force recommendations against routine prostate [cancer screening](#) for healthy men. Giuliani and Torre, both high-profile prostate cancer survivors, claimed the prostate-specific antigen (PSA test) "saved their lives," and that moving away from routine screening would imperil the lives of millions of men. The [physicians](#) working to educate the public about the science behind the new recommendations struggled to control the discussion in the face of these emotional, fear-based appeals.

"As physicians, we use narratives all the time to communicate information so our patients can make the best possible individual health

decisions. Why should we stop at the facts and figures when it comes to translating and communicating medical science? " asks lead author Zachary Meisel, MD, MPH, MS, an assistant professor of Emergency Medicine and a senior fellow in the Leonard Davis Institute of Economics. "Just like we use stories to help patients make sense of illnesses, we can use stories to help people truly understand medical science and science policy."

In a commentary published in the November 9 issue of [JAMA](#), Meisel and Jason Karlawish, MD, a professor of Medicine and Medical Ethics and a senior fellow in the Leonard Davis Institute of Health Economics, outline their ideas about how physicians can themselves incorporate narrative into the promotion of new evidence-based health care information. Their recommendations – suggesting a close link between data and personal stories that bring it to life -- have broad implications for the way in which medical experts communicate about new study results, FDA decisions, and new guidelines such as the option to wait until age 50 for routine screening mammograms.

"Scientific reports are genuinely dispassionate, characterless, and ahistorical," they write. "But their translation and dissemination should not be. Stories are an essential part of how individuals understand and use evidence." Just as the media often uses the personal experiences of patients to put a face on new medical research in their reports, the authors suggest physicians themselves should employ this strategy in a way that buoys the credibility of otherwise dry or confusing statistics – especially when they anticipate new science or guidelines will prompt confusion or negative reactions from the public.

Claims questioning [vaccine](#) safety, for example, are an area where the authors believe counternarratives would add substantial weight to evidence produced via rigorous scientific study. Actress Jenny McCarthy's public proclamation that she does not need studies to prove

that the MMR vaccine caused her son's autism because her "son is her science," for instance, could have been abutted by counternarratives such as a story from parents whose infant, too young to be vaccinated against measles himself, became sick after exposure to an unvaccinated child. And to Michele Bachmann's recent televised comments about a woman who, she said, told her that the HPV vaccine caused her daughter to become "mentally retarded," physicians may have been able to work with women who developed cervical cancer following HPV infection – which is estimated to infect as many as 80 percent of sexually active Americans at some point in their lives – to add their voices to the public discussion and play a role in de-stigmatizing the vaccine.

Shedding light on the process of scientific discovery and the creation of guidelines can also be a valuable tool in helping the public have faith in the work physicians do in the interest of health promotion. Since, as in the case of the U.S. Preventive Screen Task Force's newest recommendations on screening mammography for breast cancer detection, the process of developing guidelines is often fraught – with disagreement among experts, political pressures and gaps in data – the public would likely benefit from hearing stories about how science evolves, and the difficulties experts often face in making decisions that are best for the population as a whole.

Narratives have a place not only in illuminating science's successes, but also its disappointments, as in the case of the failed promise of the drug Avastin, which the FDA recently ruled could not be approved for use in breast cancer treatment since it failed to prove its efficacy and was, in fact, associated with serious side effects, including death. "Real and personal narratives can be told that embody, with characters and action, the evidence of a risky intervention," the authors write. "The public needs to hear the stories of patients, and their families, who encountered a drug that offered hope but was ultimately ineffective and even dangerous."

Provided by University of Pennsylvania School of Medicine

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