Narrative vs Evidence-Based Medicine—And, Not Or

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THE WEEK BEFORE THE US PREVENTIVE SERVICES TASK Force (USPSTF) released its recommendations against routine prostate screening for healthy men, celebrity patients including Joe Torre and Rudy Giuliani had already lined up to challenge the population-based recommendations. To promote their position that screening for prostate-specific antigen is lifesaving, these individuals relied on a powerful tool: their own personal narratives. However, the experts whose goal is to disseminate and translate population-based evidence will, in the name of science, shun individual stories. This one-sided use of narrative has played out repeatedly, from the USPSTF recommendations on screening mammography to the US Food and Drug Administration (FDA) labeling hearings on bevacizumab for advanced breast cancer.[1,2] Each time, those who espouse only evidence—without narratives about real people—struggle to control the debate. Typically, they lose.

Patients and families have a right to tell their stories. But what about scientists? Facts and figures are essential, but insufficient, to translate the data and promote the acceptance of evidence-based practices and policies. Narratives—in the forms of storytelling, testimonials, and entertainment—have been shown to improve individual health behaviors in multiple settings.[3,4] Moreover, evidence from social psychology research suggests that narratives, when compared with reporting statistical evidence alone, can have uniquely persuasive effects in overcoming preconceived beliefs and cognitive biases.[5] Therefore, although narrative is often maligned as anecdote and thus scrubbed from the toolbox of guideline developers, epidemiologists, and regulatory scientists, these experts should consider narrative to develop and translate evidence-based policies. This is especially important because the federal government has made substantial investments to improve the dissemination and translation of evidence from comparative effectiveness research and patient-centered outcomes research.[6]

Scientific reports are genuinely dispassionate, characterless, and ahistorical. But their translation and dissemination should not be. Stories are an essential part of how individuals understand and use evidence.[7] A narrative—defined as a cohesive story with a beginning, middle, and end—includes information about scene, characters, and conflict and raises questions and provides resolution.[4] From this framework, stories that link individuals and their experiences to evidence are tools to translate (not drive) science without introducing anecdotal bias.

Scientists can use narrative in at least 2 ways. First is in the form of counternarratives, designed to neutralize stories that promote disproven theories. Take the largely negated theories of a causal link between childhood vaccines and autism. As recounted by Offit in his book on this topic, a celebrity actor claimed that she does not need real science to know that the measles-mumps-rubella (MMR) vaccine triggered her son's autism: "[My son] is my science," she stated on television to thunderous audience applause.[8] Such narratives, challenging scientists who come to the table (or television studio) armed only with data, often succeed in the court of public opinion and weaken efforts to promote evidence-based health decisions.

When scientists encounter stories that promote unscientific approaches to health and health care, they should deploy an evidence-based counternarrative. The story of a mother in San Diego whose infant, too young for the MMR vaccine, became sick after exposure to an unvaccinated child with measles would add persuasive weight in a debate with the actor mentioned above.[9] These counternarratives may also be useful when the evidence addresses individual risks as well as effectiveness. The FDA's decision to remove breast cancer as an approved indication for bevacizumab was based not only on the absence of evidence to support its effectiveness in a general population but also on the relatively high risks of serious individual adverse effects, including death.[10] In such cases, real and personal narratives can be told that embody, with characters and action, the evidence of a risky intervention. 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.

Another role for scientific narrative is found within the process of evidence discovery and translation. Typically, experts present a "clean" version of their findings without any narrative about how they made sense of the data. This ful-

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fills the scientific virtues of objectivity, coherence, and synthesis. When the USPSTF released its report on screening mammography to much controversy, it included no narrative about the process. Only later was the story of the task force deliberations revealed. This narrative, with multiple characters operating within the context of historical precedents, timing mandates, and a messy political milieu, created a substantially more compelling perspective.[2] But the account came too late to engage a confused and angry public with the task force's conclusions. Guideline developers could include as part of their reports the narrative of their internal workings: *We started with what we knew, we looked at the evidence, we revisited our hypotheses, we argued about the findings, and ultimately we acted here and now because it was prudent, but there are more data to come, and here is what we plan to do as we learn more*. Such stories could increase trust and therefore improve the translation of evidence for individual use and public policies.

When should scientists deploy narrative techniques for evidence dissemination? We propose 2 instances. First, before public release of results, scientists should discuss with each other the stories of how they reached their conclusions. The more compelling their individual stories and the more the stories coalesce to a final conclusion, the more credibility their recommendations may have in the eyes of the public. In contrast, conflicting narratives suggest challenges in translation and argue for revisiting the process. Second, narratives have been shown to be most helpful for boosting clarity and believability of a health message if recipients identify with characters from the stories.[4] Therefore, the stories of individuals (patients, physicians, and scientists) whose experiences relate to the science should be shared when the expert community anticipates confusion or negative reactions to their evidence-based conclusions.

Stories help the public make sense of population-based evidence. Guideline developers and regulatory scientists must recognize, adapt, and deploy narrative to explain the science of guidelines to patients and families, health care professionals, and policy makers to promote their optimal understanding, uptake, and use.

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