A PIECE OF MY MIND

Story as Evidence, Evidence as Story

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One morning last year, driving between my clinic and our medical school, I tuned in to the middle of a locally produced, nationally respected radio news program expecting a conversation about the latest international crisis. Instead, the guest was a clinician-scientist discussing several recent articles challenging our current beliefs about and uses of mammography, including underreporting of harms, high rates of false-positives, screening-age controversies, and how women would make different choices if they knew the true risks. As I listened, I thought, Wow, this physician must have had media training. In point after point, she reduced complex data into easy-to-understand considerations without dumbing down the information. The host and callers clearly respected her. She came across as smart, warm, and articulate. I was impressed.

Then the host took a call that changed everything. The caller said that her sister had been 42 years old with two small children when a breast cancer was found on her mammogram. Her sister, she explained as her voice rose in pitch and faltered just a little, had been through hell for treatment but was alive to see her kids grow up—all thanks to the mammogram. The caller didn't understand how someone could possibly advocate against a test that saves lives.

The host expressed his sympathies, and then there was an expectant moment in which I tensed on behalf of my unseen, unknown colleague. She hadn't taken an antimammogram position, though when she discussed the new studies, I could see how the caller had come to that conclusion. The issues were complex and nuanced, and the physician-expert had been working hard both to respect the science and to allow for a multiplicity of perspectives.

She began her response by congratulating the caller on her sister's good health and acknowledging how difficult the experience must have been for their entire family. Her tone of voice and choice of words made clear that she was a compassionate human being and a skilled clinician concerned first and foremost with patients' well-being. Then she returned to the evidence and its implications for patients. She discussed the difference between what's good for populations and what's good for individuals, elucidating the science and statistics behind such distinctions with what appeared to be effortless clarity. She concluded by explaining that mammograms did more harm than good to most 40-year-old women, and there was no evidence that they save lives.

In those last few minutes—minutes in which the physician-expert was as articulate and personable as she had been previously—the feel and potential of the interview changed. The shift became apparent immediately as the host and subsequent callers challenged her in ways they hadn't previously. And it got worse from there. On the defensive, she cited more studies, fortifying her arguments with facts about breast cancer and the various strengths and limitations of imaging technologies. By the time I arrived at my destination, the show had shifted from an engaged conversation about new research into a subtly tense discourse that had less to do with mammograms than with the differences in how physicians and patients talk about what matters most.

While there are multiple possible explanations for why the interview went awry, it comes down to this: in the public arena—outside medicine—if you counter the personal with the professional, the human with the scientific, more often than not you will find yourself in trouble. It's a matter of using the appropriate tool for the task at hand. In this case, what the radio show listeners had needed was not more facts but another story, one as compelling as the caller's and that also illustrated the science and the different perspective it supported.

Evidence matters, but so too does the means by which we relay it. In fact, sometimes, as in this case, selecting the wrong means for one's audience can be unproductive or even counterproductive. As journalists, marketers, fundraisers, and politicians know all too well, the best strategy for education and persuasion in the public arena is usually a story that shows rather than tells how the salient facts are relevant in a particular life. If a person's sister (wife, daughter, lover, friend) has breast cancer, and that cancer was found by a mammogram, they are not interested in populations. He or she is only interested in the sister. In that context, science seems cold, clinical, and uncaring, perhaps even irrelevant. By contrast, another story, one with the same drama, passion, and power as the caller's sister's story, of how the mammogram harmed someone like their sister, might convince that person otherwise.

In medicine, we give primacy to objectivity and big data. Rational, evidence-based arguments are expected and respected as the best approach to the important issues in health and health care. We also have clear notions of what constitutes expertise. For us, an expert is a clinician or scientist with particular accomplishments, including large numbers of patients treated with the condition in question or significant research and publications on the topic. This sort of evidence and expertise is valued outside medicine too, but not always and not exclusively. In the public arena, the N-of-1 personal experience is considered not only data worthy of consideration but also sufficient to establish expertise. With a frequency and consistency that should make those who question the role of anecdotes in discussions of medicine and science rethink their position, a single, well-told story of human suffering trumps the most eloquent explanation of a large-scale trial. A quote,

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attributed to Josef Stalin, says it best: The death of one man is a tragedy. A million deaths is a statistic.

Mounting data, and the entire historical record across cultures and continents, suggest that human beings are uniquely wired for story and that stories, with their linking of the cognitive to the emotive, are often both more memorable and more persuasive than other sorts of information. As development officers and other fundraisers are fond of saying: tell the public about an entire imperiled population and you barely get their attention, focus on one family and you begin to get traction, but tell the story of a single individual and then the donations flow. And it's not just money that follows this pattern; it's most forms of behavior, including those related to personal and societal health.

We in medicine have been slower to appreciate the power of anecdotes and stories as tools for public communication, education, and advocacy, though medical centers have caught on faster than individual health professionals. This may be because unlike most other professions, those of us in science and the health professions received little or no training in persuasive communication. We have assumed that the same skills needed for articles in medical journals will be equally effective with different audiences and across all settings and mediums of communication. If this assumption was ever true, it clearly is proving false in this era of social media, blogs, reality television, ubiquitous marketing, and narrative journalism. Moreover, the change is evident not only in public discourse but with medicine as well. The last ten years has seen marked increases in the numbers and prominence of narrative and essay sections in medical journals, physician-authored op-eds, medical blogs, videos and podcasts, and sessions at professional meetings on using these modalities to educate and advocate for health and health care. Taken together, these activities constitute a new form of communication in medicine. In the 21st century, health professionals must be aware of and, if relevant to their careers, competent in not only clinician-patient and scholarly communication but also this new modality that I call public medical communication.

How might the mammogram expert on my radio have used story to more effectively make her case? One possibility would have been to tell the story of her own struggle to incorporate the new data into her clinical practice, research, or personal health decisions. That approach would have aligned her with her listeners as a fellow human being wrestling with the challenge of the new studies to her long-held and much-valued mammography beliefs and practices. Another option would have been to offer a counteranecdote, not one chosen at random or inconsistent with the best evidence, but one selected to embody the alternate perspective suggested by the new studies. That sort of story would have been most effective if it was as personal as the caller's, such as a story about the physician herself, or her own sister or mother or daughter or, if none of those were possible, about a patient for whom she felt obvious affection.

In her position, I know just the story I would have selected, and it comes not from my practice but from what happened to my close friend, whom I'll call Elizabeth. I would begin by saying that Elizabeth, like the caller's sister, had a good life and loving family. And then, at her primary care physician's recommendation, she had her first mammogram, which was, as we like to say in medicine, "grossly abnormal." She was called back initially for a diagnostic mammogram and then for an ultrasound with biopsy. After the ultrasound, she was escorted from radiology to the cancer center, where she was given an immediate, urgent appointment after 5 PM at an academic center where most appointments take months. Over the next three weeks, she had several more mammograms and ultrasounds and 2 MRIs suggestive of a large, aggressive tumor; findings in the other breast that required investigation ("Probably nothing," she was told, "but once we've seen it … "); and 22 biopsies, several of which resulted in painful collections of clotted blood in her breasts.

Normal life and work were impossible. Elizabeth and her family endured a Thanksgiving punctuated by tears and carefully chosen words so as not to increase the already-suspicious children's concern. Meanwhile, her physicians were at war: based on the x-ray films, the radiologists argued she had metastatic cancer with a less than 50% chance of 5-year survival, while her surgeons, based on the biopsy pathology, contended she had a rare, mostly benign condition. Fortunately, the surgeons were right. Still, sorting that out took weeks, and because the condition was associated with increased cancer risk, they insisted on bilateral surgery to remove all of the suspicious areas. So Elizabeth's mammogram didn't find cancer, but it did lead to the permanent mutilation of her breasts, huge medical bill copays, significant lost time from work, months of extreme stress, and ongoing anxiety about her disfigurement and risk of cancer.

At that point, the expert would have had the audience's attention. At that point, the data could make their entrance: "And Elizabeth is not alone. A recent, high-quality study showed … "

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