The Celebrity Effect
What happens when famous people reveal their health problems

By Carmen Peota

Shortly after movie star Angelina Jolie announced in a New York Times article in 2013 that she had undergone preventive double mastectomy, Twin Cities oncologist Barbara Bowers, MD, posted this on a blog site: “Kudos to Angelina Jolie, who had the strength of character to not only have a life-preserving treatment for familial breast cancer, but to share it with us.”

Bowers thought Jolie not only had made a wise personal decision, as she was indeed at high risk for cancer because she had a BRCA1 gene mutation, but also that she had handled her announcement about it with aplomb. “She made a statement. She didn't make a huge number of appearances, and she didn't go into anything but the facts about her decision. That was a class act,” she says.

What happened immediately following the announcement was another story. Jolie, considered by many to be one of the world’s most beautiful women, became the topic of endless discussions online, in print, and on television and radio. Had she made the right decision? What should other women do? “There were so many people talking on both sides that it left young women who were in the same position confused,” Bowers says. Many ended up in their doctors’ offices.

Bowers, a breast specialist who practices with Minnesota Oncology, found herself trying to convince patients with small tumors that they were ideal candidates for lumpectomy and radiation rather than mastectomy. Others who had neither breast cancer nor a BRCA gene mutation thought they needed to make the same choice Jolie had made because a family member had breast cancer. With each concerned patient, Bowers carefully explained that a small group of women have a genetic predisposition. That only one in 10 women with breast cancer have a family history of the disease. That only about 50 percent of those have a genetic abnormality. And that there is no scientific benefit to having the breasts removed if there is no family history and genetic mutation.

Then she’d try to help them understand their own thinking. “I wanted them to acknowledge why they were making the decision and what they were basing the decision on,” she says. “People are so involved with celebrities—they get to know them in their minds, who they think they are and what they are and what they represent—that when something like this happens, they take it personally and they start internalizing the emotion. And sometimes they make decisions they regret later.”

Oncologists and surgeons around the world were having similar conversations with patients, and women were lining up for genetic tests. One study in the United Kingdom found demand for BRCA 1/2 testing almost doubled in the months following Jolie’s announcement and there were many more enquiries about risk-reducing mastectomy. The impact of Jolie’s announcement was so great that Time magazine put her on its May 27, 2013, cover with the headline “The Angelina Effect.” By the end of 2014, the phrase had made it into the titles of six Angelina Jolie and Michael J. Fox are two celebrities whose health issues have influenced the dialogue between patients and physicians.
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Worship culture

Of course, Jolie wasn’t the first well-known personality with a health problem to cause a stir. Rock Hudson’s 1985 announcement that he had AIDS brought that epidemic out of the shadows. Earvin “Magic” Johnson’s 1991 revelation that he was HIV-positive further raised awareness and led to an increase in the number of people getting tested for the virus. Ronald Reagan’s 1994 Alzheimer’s announcement reduced the stigma associated with that disease. Katie Couric’s efforts related to colon cancer sparked an increase in colonoscopies. Even former Vice President Dick Cheney’s left ventricular assist device (LVAD) implantation and subsequent cardiac transplant made an impact: According to a study published in the American Journal of Cardiology last year, there was a significant spike in Google searches, YouTube videos and Twitter messages related to LVAD and heart transplantation during the time he was undergoing the procedures. (A similarly designed study found online information-seeking related to the genetics and risk-reduction resources available from the National Cancer Institute increased dramatically after Jolie’s announcement as well.)

Why these revelations have such an impact on people’s health behaviors and collective thinking is certainly related to our general interest in celebrities. There’s no doubt we have an insatiable appetite for knowing the details of their lives. Psychologists call the fascination “celebrity worship” and say it can take forms ranging from the benign (entertainment) to the psychotic. An article in HealthDay News attempting to explain this following the death of super-celebrity Michael Jackson cited experts who said celebrities tap into the public’s primal fantasies, that celebrity worship is a symptom of a rootless culture in which people feel a sense of isolation, and that as religion has waned, we’ve become more fascinated by celebrities.

We seem particularly intrigued by their infirmities. Search the web using the terms “celebrity” and “disease” and you’ll turn up thousands of sites where you can read articles like “10 Sexy Celebrities Who Have Diseases,” “10 Celebrities with Chronic Illnesses,” “15 Celebrities with Autoimmune Diseases.” There’s even a “Celebrities with Your Disease” site, where you can pick your disease and find a rock star or actor who also has it.

How celebrities’ influence affects our health choices is a question authors Steven J. Hoffman and Charlie Tan of McMaster University attempted to answer in an article published in the British Medical Journal in 2013. The authors examined theories and studies from psychology, economics, marketing and sociology. Among their findings: Celebrities activate our natural tendency to make decisions based on how others have acted; they influence us because we associate success in one area—say sports—with competence in another—say medicine; we follow the advice of those who match how we perceive or want to perceive ourselves. We follow their celebrity lead to gain social status. And on and on it goes.

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The Fox factor

Arguably, no celebrity has made more of an impact on medicine than actor Michael J. Fox. Interestingly, that impact has been felt more by scientists than patients. Beloved particularly for the roles he played on the 1980s television series “Family Ties” and in the “Back to the Future” movies, Fox not only told the world in 1998 that he had Parkinson’s disease but then leveraged his fame to start the Michael J. Fox Foundation for Parkinson Research, which since 2000 has funneled $450 million toward efforts to cure the disease.

University of Minnesota neurologist Paul Tuite, MD, recalls being skeptical when he first heard about the Fox Foundation. “We weren’t sure what that was going to be,” he says, explaining that there were already two large national organizations for Parkinson’s. He was worried the Fox Foundation would compete with them for funds. However, he quickly saw how Fox’s connections in Hollywood and elsewhere allowed him to tap sources the others hadn’t. “They generated so much funding that the other Parkinson’s organizations seemed to step aside,” he says. The National Parkinson Foundation and American Parkinson Disease Association still fund grants, he says, but when it comes to large funds, Fox is the one to go to other than the NIH.

Further, the foundation altered the direction of research, establishing its own scientific advisory committee and setting its own priorities. “In essence, it generated massive amounts of funds and is dictating, not in a bad sense but in a good sense, what areas of research should get funded and how to leverage things so people can get larger federal funds as well as move towards a cure,” Tuite says.

One of the things the Fox Foundation has done is push industry. Tuite notes there had been a dramatic slow-down in drug development for Parkinson’s. “Big Pharma had dropped the ball because they view neuroscience as not a profitable area of drug development,” he says. “Fox has pushed the study of isradipine, a blood pressure pill, which is now in clinical trials in the Twin Cities. So it’s a new model of bringing drugs to the marketplace.”

As a researcher, Tuite personally has felt Fox’s influence. In addition to the isradipine trial, he’s been part of a Fox Foundation-funded multi-center study called BioFIND. The goal is to discover and verify biomarkers of Parkinson’s disease. The study is being carried out at eight academic sites in the United States. BioFIND is collecting clinical data and biospecimens, including blood and cerebrospinal fluid, from 120 people with well-defined, moderately advanced Parkinson’s and 120 healthy controls.

Tuite says that for many years his Parkinson’s patients did ask him about Michael J. Fox. “They all wanted to know what he was taking,” he says. “Most people are not asking that anymore. But many are happy that he’s out there and wonder how it’s changing things research-wise.”

Carmen Peota is an editor of Minnesota Medicine.