LIFTING DEATH’S VEIL

A Conversation with Dr. Atul Gawande on Death and Dying in America
H arvard surgeon and New Yorker writer Atul Gawande’s powerful book Being Mortal explored death and dying in America and rose to the top of the bestseller lists, but it was a nationally broadcast FRONTLINE documentary of the same name that catapulted him to the forefront of the national conversation about end-of-life care. In an era when more and more medical treatment often doesn’t allow people’s lives to end the way they want, Gawande’s message has never been more important.

In 2015 the California Health Care Foundation and the John and Wauna Harman Foundation created a community engagement campaign in California centered on local screenings of the film. As chronicled in a new report about the project, these events attracted a more diverse audience than the television broadcast—and one receptive to the film’s message. As a result, the Harman Foundation plans to extend the campaign nationwide.

I recently spoke with Gawande about his experience filming “Being Mortal” and how far America has come in talking about death and dying. The conversation has been edited and condensed.

With Being Mortal you’ve become the face of a movement. What reaction do you get when you talk to people?

People come up and tell me about their dying mother or their dying father or their family member in a nursing home and feeling that they were able to have conversations about what really mattered to them. And that’s incredibly gratifying. It’s the number of people who tell me their stories, and they are feeling that they can have these conversations that defined what mattered most to them or to their family—and in many cases, translated into the doctor’s office, where they can advocate for themselves. I’m definitely also seeing the conversation among my colleagues—doctors and nurses—who are finding the words to ask people about their fears and hopes and the limits that they would place around what they’re willing to endure.

Why did you decide to participate in a film based on your book Being Mortal?

A book creates one kind of understanding. The FRONTLINE film seemed like an incredible opportunity to show another dimension of the story and reach an even larger number of people. There’s seeing it visually and watching as people confront these situations, see what they say, what they don’t say, what they look like, what they’re struggling with. And then you add in that I got to do it with the director, Tom Jennings, whom I went to high school with.

What was it like co-writing a film?

We were co-writers, but Tom was definitely the lead writer. I know how to tell a story in words, but to depict sometimes-complex ideas visually is very hard. He struggled for a while with the fact that this was not black-and-white. When he started out the filming, what he wanted to see was the black-and-white comparison of the doctor who thinks that all of this is hogwash and the doctors who think that this is the right way to go. A classic sort of battle. Instead, the real story is that even experienced clinicians find these conversations difficult, and that the difference between having a really good outcome and a conversation that doesn’t go so well is subtle. You could see it in the film. You could see it in the difference between the family that’s willing to ask the hard questions or the doctor who’s willing to just sit in silence with bad news and let the patient absorb it. And then you could see the other situations where the doctor or the patient is uncomfortable and not able to sit with these ideas.

Tom found a way to get that reality across. I guess the way I’d put it is that he found a language and he found a visual story that could explain how this is not good and evil. These are good doctors and struggling patients. And in one case, they have the right words. They ask about fears and hopes and what people are willing to sacrifice and what they’re not, and you can see how differently the story unfolds when they do that. On the other side, you see the people who don’t ask—more out of anxiety, discomfort, or even inexperience than disagreement.

DIGITAL SPOTLIGHT

Being Mortal

FRONTLINE follows renowned New Yorker writer and Boston surgeon Atul Gawande as he explores the relationships doctors have with patients who are nearing the end of life.

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The book seemed geared for a general audience, while the film seems possibly even more relevant to doctors. Was that the case? It was both. Partly we were letting a general audience see the anxiety and struggles that clinicians have and let them acknowledge on film how hard they can find these conversations, and really dissect why did you say that at a certain point. The film removes a certain mystery for people about what’s happening in these conversations, not just for the doctors but for families as well. And then you see someone like the lawyer who goes to New Hampshire for his last weeks.

This is Jeff Shields, the person who went up to his farm?
Yes. You see an example of someone who kind of takes control. He has this great moment when he says to the doctor, “I know you’ll tell me when I reach the point that I can’t do what I want, which is to be able to still be at home and not in the hospital. I know you’ll tell me that, won’t you?” He was signaling in a very gentle way. “This isn’t the place I want to be, and at a certain point, I want you to have this conversation with me.”

The patient opened the door. He was very clear about what he did not want to sacrifice. You know, if things got bad, he wanted to be home. He wanted to be out of pain. He wanted to be with his family. He wanted to have that time on hospice.

You got to see how different that was from the woman who didn’t have that conversation until toward the very end. Finally, someone asks enough questions to find out that what she really wished for was that she could go to Disney World with her grandchildren. You’re watching, and you’re realizing that they could have given that to her. They could have made that possible for her, but now it’s too late, and it’s not going to happen, and it’s heartbreaking. To see that contrast is a lesson for me and my colleagues—it’s a lesson for all of us.

How did you end up selecting the families? Was it difficult to get their involvement?
The short answer is it was anybody and everybody who came in through the door and was willing to be filmed. You start with, say, 50 people. Ten might be willing to be filmed from the time of their diagnosis. As they go along with their diagnosis and things get worse, and then you get to that pivotal conversation, you might be down to two who are willing to still have the cameras in there. And I don’t know entirely the reasons, but it’s undoubtedly a mix of the demographics in Boston and at the Dana Farber Cancer Institute. Also, you have an even more complex circumstance of minorities or non-English-speaking people who were even harder to include as part of the story. Then you had other folks who found it challenging enough to have communication with the doctor, and now it’s even tougher with a camera in the room following you around.

We filmed for two years. You start out following people along the way. You had a pretty diverse population when you started, but by the time you have the group of patients who are actually willing to let you continue that story all the way through, it’s individual idiosyncrasies that determine who is comfortable letting you be in the room as they expose some of their deepest vulnerabilities and the clinician is exposing some of their own doubts and difficulties.
What’s interesting is that there were attendees at our screenings who said that they didn’t “see themselves” in the movie. But they also said, “These stories are incredible, and I relate to them.” Illness, especially terminal illness, is the great equalizer. People are stripped down, pared down. What they have doesn’t matter anymore. They’re each characters managing and battling in different ways. The woman who couldn’t go to Disney World came from a different economic background than the professor of law. And you’re seeing her struggle out of her own character, which is partly defined by that, but not entirely by any means.

One thing I definitely discovered is that everybody’s experience and story is individual. It certainly is the case that people who are non-English speaking, people who don’t have a college or a graduate education, people who are minorities, have additional barriers that push against their being able to have a connection with their clinician. They may be less able to feel that they can explore, “Here’s what I’m afraid of; here’s what I’m hoping for; here’s where I draw the line.”

Yet sometimes you see people whose personal character and their strength, and the way they’ve had to gut lots of things out in life, lead them to be very straightforward and clear with clinicians. Other folks are completely beaten down by the system. There are barriers and circumstances that make it particularly tough for communication and trust to allow those difficult conversations to happen.

You’ve spoken about a “societal learning curve” with death. Where is the country now?

I said in the book that I thought the U.S. was moving quite fast. In 10 years, we’ve gone from less than 20% of families dying at home or with hospice to where we’re at about 50% now. That’s in a pretty rapid
period of time. When I grew up, everybody died in the hospital. You know, I’d never seen anybody who’d died until I was in medical school. Now, each of my kids has been in the home of somebody who was on hospice, because it was a mother of a family member or my daughter’s piano teacher or those kinds of circumstances. And suddenly, that makes it feel much more normal, that it’s part of life. In that sense, we’re lifting the veil.

What do you think will happen as a result of California’s aid-in-dying law?
The way I’d look at it is that there is a small percentage of the population, it’s about 1% or less—in states like Washington, Oregon, and Vermont—who seek assisted death at the end of life. I suspect it will be a very small percentage in California as well. One of the critical things to understand is that it’s virtually all of us who end up wanting to be sure that the goal we’re trying to achieve is not necessarily a good death but a good life all the way to the very end. The vast majority of people have concerns about the care they receive not being in alignment with what matters to them most. When that care is out of alignment with their priorities and goals, the result is suffering.

These are two very different debates. I worry that they get conflated. This is not just about the very last few days of your life. This is about the journey of being a mortal being. You will have a phase of your life where you will become frail or endure a prolonged sickness. How do we have the imagination and the help to assure that you have the best possible days in the time that you have? And whether you might want assisted death at the end of that or not, we’re not delivering what matters most to people. That, I think, is what people are responding to at the largest level.

As a doctor you’re exposed to so many stories. Are you constantly making mental notes?
It’s funny. When I’m in the operating room or in the examining room, I don’t really register those experiences as stories to write about. It’s much more common that I think about problems that I’m confused

KEY STATISTICS

Figure 1
Number of End-of-Life Days in Hospital (by State)

Figure 2
“Being Mortal” Viewership, by Race & Ethnicity
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about. For example, writing Being Mortal came out of many experiences where I felt incompetent taking care of people whose problems I was not going to fix. I wanted to know how to feel better in those conversations. That’s when I pick up the pen. It’s my way of thinking through the problems that I don’t understand and trying to find my way through confusion. And so then I’m probing the stories and I’m talking to people. I’m describing what happens as I work my way through those problems. Whether it’s things that bother me like, Why are health care costs so high? Or, do we really have a problem of unnecessary surgery? And here I am a surgeon. Or what is it that we want to happen when someone is up against a terminal illness and getting worse? How can I do better in that circumstance? That is the impetus—to think through the reality of the story.

Since we’re talking about film, what were your favorite movies this year? Spotlight. It’s amazing and such a Boston story. Better, I thought, than even All the President’s Men. I watched everything from Star Wars to Sicario to The Big Short.

So Spotlight number one?
If Spotlight doesn’t win an Oscar, I’ll be...Well, I shouldn’t be surprised. My movies never win.

Steven Birenbaum is senior communications officer at the California Health Care Foundation, where he promotes the foundation’s research and initiatives via print, digital, and video media. His work has appeared in The New York Times, Newsday, KQED, and other news outlets.

Editor’s Note: Spotlight did in fact win the Oscar for Best Picture and Best Original Screenplay in 2016. ©A.M.P.A.S.®

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