

Book and film

From narratives of illness to “edutainment”

Depending on how it is used, “edutainment” is either a dirty word or a welcome concept. The basic idea is simple. UN Secretary-General Kofi Annan defined it succinctly in a speech earlier this year, in which he urged broadcasters to use airtime to increase knowledge of AIDS: “If a well-known character in a popular television series has to confront HIV or AIDS, this can have a dramatic effect on viewers who may not have watched a non-fiction programme about the epidemic.”

In the USA, where a sizeable percentage of the population seems to prefer to get their health messages from the internet, such efforts have often been relegated to the realm of secrecy. In 2000, <http://www.Salon.com> reported that the federal government has approved and sometimes even altered the scripts of popular network television shows to fit with its anti-drug messages.

Richard Pellegrino has his own brand of “edutainment”. Pellegrino is not a movie producer or a novelist. He is a neurologist in Hot Springs, Arkansas, who treats patients with multiple sclerosis, some of who are enrolled in the clinical trials he helps to run. But Pellegrino decided that writing fiction and creating documentaries, what he calls “translational entertainment”, is an important part of his practice.

“The cornerstone is accurately translating the patient experience into fictional characters and also translating it into non-fiction”, Pellegrino told *The Lancet*. He started his project by asking patients with multiple sclerosis to send letters to him via his website about their lives and experiences of illness; he got hundreds of replies, from across the USA and around the world.

Many health education approaches involve finding extraordinary patients who scuba dive or achieve other amazing things. But, after reading the letters,

Pellegrino concluded that such approaches could make patients feel inadequate. “This guy is jumping out of airplanes and deep sea diving’, patients say, ‘and I can’t get out of bed in the morning. It must be me.”

Pellegrino’s idea was to use the letters to create a novel and a documentary: the medical thriller

“They all read it and called me crying . . . it made them realise what I’m going through and will be going through. I’ve gotten closer to some of my family members”

Point Source, and the documentary *Taking Back the Future: Living with MS*. *Point Source* is the story of an intrepid Italian-American neurologist and medical sleuth in Hot Springs, Arkansas—other than her gender, she might be Pellegrino—who is presented with a cluster of multiple sclerosis cases that turn out to be connected to international intrigue. “The mission of the project is to provide a media voice for patients and the reason for doing that is to create products like the novel and the documentary that are handheld, to promote understanding among family and friends”, said Pellegrino. “A patient can hand you the novel or DVD and you can have a better understanding of what she’s going through.”

His project thus expands the field of narrative medicine by using entertainment as a sort of lure to induce others to read the letters he received—a selection of which appear at the end of the book and are read out at the end of the film. “If we’re comparing this approach to a more straightforward approach in pamphlets or books, I think that I wanted to use the power of story”, Pellegrino said. “Most people will agree that a good story draws you in. It

forces you to imagine yourself in the shoes of the character.”

Pellegrino didn’t have a specific methodology for using the material, and in fact by the time he began reading the letters, he had already drafted a fairly detailed plot. He used the narratives in the letters to fill the plot in with characters. “It gave me a gold standard to always go back and check myself against”, he said. “I already knew from my perspective as a physician what I thought multiple sclerosis patients went through. But I knew you only got one angle. I went back to the letters to make sure that the characters were real.”

The result is a page turner with the conventions of many popular thrillers: dashing heroes who just so happen to have known the villain earlier in their lives, a “good cop” the heroine seems to have a crush on, a “bad cop” who is more interested in his career than the truth, and an extraordinarily well connected good-godfather figure who is called on by the main characters for help. It’s not high literature; but while some of the character development seems a bit forced, it is effective, particularly for a first effort.

The version of the movie I viewed was a bit rougher. One of the decisions Pellegrino and his director Ken Mandel made was not to use a narrator. It’s not as though the stories aren’t strong enough on their own: one long-time sufferer of multiple sclerosis describes how he was able to walk for the first time in many years when he saw his boat sinking and got up out of his wheelchair to walk down the dock to save it.

Pellegrino is a garrulous, likeable doctor—his approachability comes through in the film, and the shots of patients going about their daily lives are powerful. Still, I suggested to him that the film might work better with



Point Source: a Medical Thriller
Richard G Pellegrino. Moments of Discovery Press, 2004. Pp 276. \$24.99. ISBN 0-9748396-0-4.



Taking Back the Future: Living with MS
Directed by Ken Mandel. More information at <http://www.YourMovieProject.com>. Premieres on Oct 23, 2004, at the Malco Theater, Hot Springs Film Festival, Arkansas, USA.

an actual narrator who introduces the film itself, perhaps gives some descriptions of multiple sclerosis, and introduces each of the patients. And he acknowledged that “we understand that we’re giving it a shot as is”. But he says one of the benefits of working independently—the book is also self-published, although both it and the film have an unrestricted grant from Teva Pharmaceuticals—is that his approach can evolve. In fact, he is now looking to narrative medicine “as a way to shed a different kind of light on the characters”. A professor at the University of Arkansas, Little Rock, is applying for institutional review board approval to work with him on future iterations of the project—something Pellegrino didn’t need for his own work, although he obtained consent from all the patients who participated.

This switch in approach may be wise, since it is the verbatim letters that may have the most direct impact—which should be encouraging to proponents of narrative medicine. “I have nine brothers and sisters”, Becky Cerrato, a 44-year-old woman with multiple sclerosis who is featured in the documentary, told *The Lancet* in a recent interview. “They all read it and called me crying. The back of the book those were the stories that really affected them and made them realise what I’m going through and will be going through. I’ve gotten closer to some of my family members. With a big family it’s hard to talk to everybody every day. But they’re very concerned about me and it’s really brought us closer together. It’s the support that I need.”

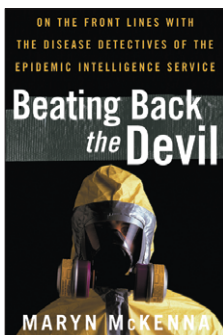
It may take a while for the book to reach others. “My husband won’t read

the book”, says Cerrato. “He said he will. But he’s a very busy guy—he has his own business. He said, ‘is this going to upset me?’ I’m working on him.”

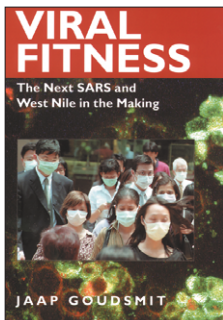
The project has a lot of promise—perhaps because it has no particular agenda. Future iterations—there is another novel in the works called *Adverse Event* that is about clinical trials, and a documentary that will use the same process—will certainly need some polishing. But it strikes me that Pellegrino is more than open to constructive criticism and that “translational entertainment” may one day accomplish far more than is currently achieved by secret messages embedded in popular television programmes.

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Beating Back the Devil: On the Front Lines with the Disease Detectives of the Epidemic Intelligence Service
Maryn McKenna. The Free Press, 2004. Pp 303. \$26.00. ISBN 0-7432-5132-6.



Viral Fitness: The Next SARS and West Nile in the Making
Jaap Goudsmit. Oxford University Press, 2004. Pp 187. £16.99. ISBN 0-19-513034-0.

In brief

Book Watching the detectives

September brought a new US television series, *Medical Investigation*, featuring a “rapid response team” that could be the CDC’s Epidemic Intelligence Service (EIS). Trouble is, the team is shown as being from the NIH, not the CDC, underscoring *Atlanta Journal-Constitution* reporter Maryn McKenna’s contention that the EIS isn’t as well known as it could be.

In *Beating Back the Devil*, McKenna tells the history of the EIS by following new recruits—physicians, public-health PhDs, etc—through their training. The officers-to-be, sent off to public-health departments, are occasionally called to drop everything to rush to the site of an outbreak—such as the 2001 anthrax attacks. But the mandate of the EIS goes far beyond bioterrorism; interspersed with the stories of the neophytes are tales of adventures past spent searching out malaria, SARS, smallpox, and tuberculosis around the world. And, as any

epidemiologist knows, unlike their television counterparts, the EIS can’t neatly solve their medical mysteries in an hour. Sometimes outbreaks just disappear—but that hardly means the effort isn’t worthwhile, or that these narratives aren’t worth reading.

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Book The fittest ones of all?

Viruses are the only inhabitants of the planet to rival humanity in successful exploitation of the environment. And, as Jaap Goudsmit chillingly demonstrates, they evolve much faster than we do. A successor to 1997’s *Viral Sex*, *Viral Fitness* is a natural history of what Goudsmit terms “the fittest of all creatures”. He elegantly proves his point in chapters that read like mini detective novels: the search for SARS, influenza’s evolution from harmless avian virus to increasingly lethal killer of people, and so on.

Viruses aren’t all bad. While bacteriophages lend cholera its virulence, they also keep populations of the aquatic bacteria in check, and may offer a way to fight antibiotic-resistant infection. In fact, viruses protect biodiversity—but by stripping forests and wiping out wild animal populations, we are putting them out of this line of work. These “cornered” viruses have no choice but to attack us to survive, says Goudsmit. Our best hope for the future, he argues, is widespread vaccination, a more realistic and likely safer goal than disease eradication.

On Sept 11, 2001, Goudsmit saw the planes crash into the World Trade Center. Witnessing the event made the “unthinkable”—an attack with smallpox or Ebola—a possibility, he writes. But as *Viral Fitness* shows, our legacy of environmental degradation is a much more serious threat.

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Profile

Massouda Jalal, presidential candidate in Afghanistan

The telephone line between London and Kabul is awash with static when I finally get through to Massouda Jalal, but the only female candidate in the upcoming Afghan presidential election comes across loud and clear. "I am confident I can win", she says. The weight of political opinion may disagree with her—most pundits predict that the incumbent Hamid Karzai will romp home once again—but there's no doubting her determination. The steel in her voice signifies a strength of character that appears to have served her well—first as a physician, then as a public-health worker, and, since 2002, as a female presence in her country's male-dominated and often deadly political arena.

Jalal began her professional life as a physician after graduating from medical school in Kabul in 1988. Her first job was in a mental-health clinic, but when that was closed during the tumultuous 1990s she switched her attention to paediatrics and took up a position in Kabul Children's Hospital. She also took a teaching post at Kabul University medical school, but the arrival of the strictly religious new rulers in the capital in 1996 put an end to that. Like other women, she was forced to quit her clinical job and give up her teaching position. "It was just announced", she told *The Lancet*. "We had no choice."

During the Taliban years, Jalal said, her only option for continuing to practise medicine was to work from home. Then, in 1999, she began working for the UN World Food Programme (WFP). She worked in women's empowerment and in a scheme setting up bakeries to give widows an occupation and income. They sold the bread at a fraction of the normal cost to poor households. But it wasn't easy operating under the Taliban, said Maarten Roest, a WFP spokesman. "They tried to shut down the bakeries", he said. "They didn't like that it was a women-run programme." After negotiations, they allowed her to continue, but life for Jalal continued to be difficult. "All the time I received threats", she said. "It was very hard."

When the Taliban were removed from power in the wake of the US invasion in 2002, Jalal was one of 200 women who were elected to attend the loya jirga, a gathering of hundreds of tribal and political representatives to choose the country's interim president. It was her first taste of politics and her desire to take part was born from frustration at the limits of what she could achieve in medicine or public health. "As a doctor, I was not able to solve the problems of poverty. I couldn't do anything about that."

Although she was warned not to, she challenged Karzai and won 171 votes in the 2002 presidential election, second to the US-backed favourite's overwhelming 1295. Her candidacy was the first time a woman had run for the top job in Afghanistan, she said. "After 5000 years of his-

tory, I am the first." She was approached about running for the vice president's job, she adds, but refused to consider it.

Later that year, her colleagues at the WFP nominated her to study at the Center for Development and Population Activities (CEDPA) in Washington, DC. CEDPA runs courses for women to learn skills and network with the aim of advancing their position in leadership roles. Jalal made the most of the opportunity, by all accounts. "We saw her as being someone who was very reflective and thoughtful", said CEDPA's senior vice president, Rosann Wisman. "She was someone who had an inner strength." Jalal told her course-mates that she was undecided about whether to run again, Wisman recalled. They egged her on. "Regardless of what happens in the election, her running for office is an inspiration to women worldwide", she said.

Since campaigning began officially in early September, Jalal's operation has been running on a shoestring budget, without major financial backing. Her campaign chief is her husband, Faizullah Jalal, a professor of law from Kabul University. Together they have three children, two daughters aged 9 and 7 years and a son aged 3 years. Although her candidacy has little money behind it, it has generated a lot of attention from the media. International outlets such as the BBC, *The Washington Post*, and NBC covered the beginning of her campaign outside one of the WFP bakeries. Jalal, who is routinely photographed wearing a pale blue headscarf rather than the all-encompassing burka, was heard by about 100 women and children, according to the BBC. "I am your servant", she said. "We all share each other's happiness and sorrow. If I win and become the president of Afghanistan, it will be a great honour for the women of the country."

For some commentators her political platform is too vague—although this is a failing she has in common with a good proportion of the 17 other candidates. "At this stage we do not know what her program may exactly be", says the *Afghan Observer* website, "a theme of her campaign seems to be advocating for more transparency in the political process as well as in the way international money is being spent in Afghanistan." Jalal herself seems clear about her priorities. "The first thing I will do will be to make a transparent and efficient system", she told *The Lancet*. And given her background, it's not surprising to hear that health and human rights are also central to her ideas for the future of her country. "I am a doctor by profession, I am a teacher by profession, I am a woman and I am a mother", she said. "Of course those things are important to me."

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