Storytelling's Power in Cancer Treatment

By Susan Jenks

When his mother began chemotherapy for lung cancer, Brian Fies started sketching, realizing only later that he had captured the essence of her day in a cartoon.

For the next year and a half, he kept drawing. In 2005, he published *Mom's Cancer*, a graphic novel that tells his mother's story of fighting metastatic disease in 115 pages of comic illustrations.

Although she lost her battle, Fies, an artist and science writer who lives in Santa Rosa, Calif., sees his book as a road map for others facing a diagnosis of any life-altering illness, not just cancer. Despite having a nurse in the family and his own exhaustive research, "we kept getting surprised," he said. "We were not prepared for many of our interactions with the medical community."

Over the past several years, graphic novels, such as *Mom's Cancer* or Miriam Engelberg's *Cancer Made Me a Shallower Person: A Memoir in Comics*, have emerged as a powerful form of storytelling—or medical narrative—about cancer. Michael Green, M.D., a professor in the department of humanities and medicine at Penn State College of Medicine, chose this medium to depict a missed diagnosis that haunted him for years. The comic, published in the *Annals of Internal Medicine* (*Ann. Intern. Med.* 2013;158:357–61), is thought to be the first to appear in a mainstream medical journal. And many medical schools, including Penn, now include graphic novels as part of broader-based narrative approaches to improving doctor–patient communication in cancer and other diseases.

Gauging the effect of these efforts, however, largely centered around literature and the arts, is difficult, experts say, because no "empathy test" exists. But few dispute their therapeutic value or their potential to foster discussions about sensitive topics—no more so than in cancer. Most important, perhaps, these stories inject empathy and self-reflection into an increasingly technology-driven

profession, they say, offering insight into patients' and even doctors' experiences.

Various other disciplines have grappled for years with improving the care of the sick, said Rita Charon, M.D., Ph.D., a professor of clinical medicine at the College of Physicians and Surgeons at Columbia University.

"But we have to keep coming up with 'hearable' means of addressing the most obvious concerns: patients' sense of isolation and their fears when faced with disease."

A pioneer in narrative medicine, Charon created a one-year master's program in this discipline at Columbia in 2009 to teach medical students and others the skills to "shift the culture" in health care and "distract them from the technical part of what they do." On the oncology side of the program, she said, the school brings artists into the pediatric clinic to, for example, help children deal with chemotherapy infusions.

"The artists let the kids create art as they're getting their infusions," Charon said, a visual storytelling technique that seems to not only change the climate of the clinic but also reduce children's defensiveness and stress. The next step, she said, will be to have patients, families, and staff in both the adult and pediatric clinics write their own narratives, to address questions about hope and expectations concerning care.

"A good medical history is like that—with a beginning, a middle, and end."

So far, some 50 students have graduated from the program, many entering it immediately after college before starting medical school, whereas others are midcareer professionals seeking to add a narrative dimension to their practice, she said. A few are poets or writers who want to teach these skills in a clinical setting, according to Charon. To measure the program's success,

she said, "we have to look at what happens when they leave."

An article by five former students touches on how the program contributed to their moral and personal growth. In "Five Voices, One Story" (*JAMA* 2013;310:2615–6), Christopher Salib, who is studying at Meharry Medical College in Nashville, cites how the William Carlos Williams short story "The Use of Force" captures a young girl's "irrationality, unspoken fear, and determination" in resisting a throat culture for a diagnosis of diphtheria.

"We medical students need to learn how to recognize, manage, and approach the

Paul Lyons, M.D.

temperament of the sick," Salib wrote. "Incorporating the use of story into medical education can help us do that. Narrative and medicine are codependent—words nurse the wounds medicine cannot describe."

Cartooning in the Classroom?

At the University of California, Riverside, "Goldilocks and the Three Bears" might seem an odd choice for a narrative medicine course, but Paul Lyons, M.D., family physician and senior associate dean for education, uses the childhood fairy tale to teach story structure to undergraduates and residents.

"A good medical history is like that—with a beginning, a middle, and end," he said. Lyons also tries to supply tools to frame a story, since patients and physicians tend to view the disease process differently. And finally, with the profession's stressful environment, he uses exercises in which students reflect on those stressors, writing or drawing pictures to describe them. Graphic novels, especially, are a powerful

medium and an artistic mode that resonates, Lyons said.

For Green, emphasizing this medium over other narrative forms arose from a combined interest in bioethics, medicine, and the visual arts. The potential of visual storytelling first struck him, he said, after reading *Maus* by Art Spiegelman, which came out in 1986.

"I thought, if you can do a comic about something as extraordinary as the Holocaust, why not medical issues?" Green said.

He now has 5 years of data evaluating students' attitudes toward reading and creating their own comics, awaiting publication.

"There's not a whole lot of research out there," he conceded, but interest is growing.

In June, for the fifth year in a row, an international conference on comics and medicine will take place, this one hosted by Johns Hopkins University Medical School in Baltimore. As an educational tool, graphic novels hold real appeal, Green said.

"So much about being an effective doctor is being an effective communicator," he added.

So far, graphic novels disproportionately deal with cancer and structural issues, such as access to care or insurance concerns,

that patients face. What's most remarkable about these stories, he said, other than transcending language barriers and the so-called digital divide, is that they offer a perspective people cannot get in any other way. For example, Marisa Acocella Marchetto's *Cancer Vixen*, if told by a doctor, would focus on the disease itself, he suggested.

"And yet, what she's most scared about is not her upcoming treatments but how to pay for them," he said. "She keeps asking whether the hospital will accept her American Express card."

Patient Videos

Gregory Makoul, Ph.D., senior vice president and chief innovation officer at Saint Francis Hospital and Medicine Center in Hartford, Conn., said he still favors unscripted patient videos as his primary narrative approach.

"It's an incredibly powerful tool, allowing patients to film their own stories" in the privacy of their homes, he said. Everyone remembers one clip, which he often shows during speaking engagements, Makoul said. In it, a young woman furiously chops onions in her kitchen as she talks about her doctor's dismissal of her questions as stupid.

To gauge doctors' communication skills (or lack thereof), Makoul said, he helped develop and holds the copyright to the Communications Assessment Tool (CAT). Funded by the American Board of Medical Specialties, CAT is now in 20 countries besides the United States and is available free to any health care provider for noncommercial use by contacting him at gmakoul@stfranciscare.org. Originally designed to elicit patient preferences, CAT has evolved to include different measures of how well patients understand what their doctors are telling them and actionable feedback for physicians, according to Makoul.

"The videos reinforce CAT because both are focused on patients' point of view," he said, "but CAT doesn't measure the impact of patients' narratives." However, he added, "I do think it's tremendously therapeutic for patients to tell their stories."

Fies would agree. Though some criticized him for making fun of his mother's illness by using a comic format, he said, neither he nor his mother saw it that way.

"I think she saw the comic as her legacy as much as mine," Fies said. "She got a lot of satisfaction from it."

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TERT Promoter Eyed With Suspicion and Hope

By Cathryn Delude

Cancer researchers yearning for a robust universal biomarker of malignancy and tumor grade have long found telomerase a tempting candidate. This enzyme maintains the telomeres at the tips of chromosomes in early development and stem cells but is then usually inactivated, allowing telomeres to erode and limiting cell division. Most cancer cells, however, reactivate telomerase in their quest to become immortal.

Current methods to measure telomerase levels for clinical diagnosis and prognosis through DNA, RNA, or protein analysis have technical difficulties, including lack

of reliable antibodies and inability to use in paraffin-embedded tissues, said Uri Tabori, M.D., from the Hospital for Sick Children in Toronto, Canada. In the past year, he and others took a different approach, looking at the promoter for the catalytic subunit of telomerase, telomerase reverse transcriptase (TERT) instead of directly at the gene.

TERT Promoter Methylation

Status in Pediatric Brain Tumors

In that study (*Lancet Oncol.* 2013;14:534–42), Tabori focused on methylation. Although methylation typically silences genes, it

can promote cancer, possibly by silencing tumor-suppressor genes. Also, methylation status can be quickly, easily, and accurately tested in clinical samples. In an initial sample of 280 malignant and healthy pediatric brain samples, TERT promoter hypermethylation characterized 72% of the malignant samples but only one healthy sample. In further analyses of different pediatric brain tumors, methylation predicted survival and progression-free survival, increased in tandem with telomerase expression, and distinguished low-grade from high-grade tumors, as well as which low-grade tumors progressed to high-grade lesions.