

How Literary Journalism Can Inform Bioethics

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Bioethics scholars can benefit from using literary journalism to explore moral problems in medicine, just as they use other genres.

There is a striking difference in how literature and journalism are each regarded within bioethics, an interdisciplinary field devoted to the study of ethical issues in clinical medicine and biomedical research. On the one hand, bioethics has largely embraced literature for its important contributions to ethical discourse. For example, many scholars in the field advocate the use of novels, plays, and short stories to teach ethics in medical schools. Kathryn Montgomery, a professor of medical humanities and bioethics at Northwestern University, is among those who have argued that literature plays a vital role in illuminating the moral complexities of contemporary health care. In a 2001 essay, she observed, “Literature has always been an important part of ethical discourse, and the discourse of medical ethics is no exception. Short stories, novels, poems, plays, autobiographies, and films vividly represent illness, disability, and dying and thus pose many of the questions addressed by ethics and public policy.”¹ There is also growing recognition within bioethics that studying the narrative techniques used in literature can help bioethics scholars develop their own narrative skills. As a result, literature has garnered a fair measure of appreciation within bioethics, both as a rich source of ethical material and as a model for effective and engaged storytelling.

Journalism, however, is regarded in a very different light. Much of the bioethics discourse on journalism has been characterized by skepticism,

criticism, even disdain. Peter Simonson, a professor of communication and rhetoric at the University of Colorado at Boulder, has observed that a pattern of discourse within bioethics has served to “symbolically distance” scholars in the field from what is often referred to simply as “the media.”² Simonson spent time as a visiting scholar at the leading independent bioethics center in the United States, the Hastings Center in Garrison, New York. Afterward, in an essay published in the *Hastings Center Report*, he noted, “There is dissatisfaction with the media within the field of bioethics. While talking to the news media is part of the job for many scholarly bioethicists, there is much grumbling about it.”³ The grumbling is not hard to find. Among bioethicists’s standard criticisms of journalists are that they oversimplify complex issues, favor “sound bites” over well-reasoned arguments, misquote sources, take comments out of context, sensationalize, and omit important factual information. These concerns have prompted some scholars in the field to question whether it is even possible to engage with journalists in ways that are both useful and morally justifiable.⁴ Thus, the bioethics discourse has drawn a sharp distinction between literature on the one hand and journalism on the other: while literature illuminates and enlightens, journalism obscures and misleads. Literature merits scholarly respect; journalism does not. Literature is worth studying for its moral content and narrative techniques; journalism offers little in terms of content or craft that bioethics scholars might find useful or instructive.

In her essay on literature and medical ethics, Montgomery made an important point about fiction, poetry, drama, and autobiographical essays. These literary texts, she wrote, explore human predicaments related to illness and dying “not because they are central to medical ethics but because illness, disability, and death are part of the human condition that imaginative writing exists to explore.”⁵ My aim in this essay is to extend that idea by pointing out that illness, disability, and death are part of the human condition that *journalistic* writing also exists to explore. My argument is that bioethics scholars should expand their notion of literature to include works of literary journalism that also offer insight into the challenges confronting patients, families, doctors, and nurses in the twenty-first century. Part of the work that needs to be done is to convince scholars who hold widely divergent attitudes toward literature and journalism that the two are not as different from each other as they may seem. Novels, short stories, and plays may appear to have little in common with newspaper articles, radio talk shows, and television news broadcasts. But, as we know, the boundary between literature and journalism is not always so clearly drawn. This, of course, is the case with literary journalism, which combines the storytelling techniques associated with fiction writing with the journalist’s aim to represent real

people and events. Classic book-length works in this genre, such as Truman Capote's *In Cold Blood*, Jonathan Harr's *A Civil Action*, and Susan Orlean's *The Orchid Thief*, have been enormously successful with both general readers and critics, who sometimes mistake these nonfiction books for novels.

Yet, despite its literary quality, writing of this kind has received little attention to date from scholars who have tried to emphasize the connections between literary writing and ethical discourse. When bioethics scholars, for example, discuss the importance of literature to their field, what they are mainly talking about are works of fiction: short stories, novels, plays, and films. Numerous essays in bioethics journals and books have focused on specific works of fiction, including George Eliot's novel *Middlemarch*, Anton Chekhov's short stories, novels by Walker Percy and Henry James, Margaret Edson's play *Wit*, and Akira Kurosawa's film *Ikiru*.⁶

Many bioethics scholars have embraced the notion that works such as these offer evocative and complex "case studies" that can assist doctors, nurses, and students training for these professions in learning to work through moral problems. William Carlos Williams's well-known short story "The Use of Force," for example, has been widely used in medical schools in the United States to explore how doctors respond when faced with a patient who refuses treatment. Some bioethics scholars have willingly acknowledged that ethics cases drawn from literature are sometimes better than the cases written by bioethicists themselves. Carl Elliott, a philosopher in the Center for Bioethics at the University of Minnesota, offered this point of view in his book *A Philosophical Disease: Bioethics, Culture, and Identity*. "Novels, plays and films can be as good or better than real cases," he observed, "for the mere reason that novelists, playwrights and film makers are better at telling stories than philosophers, lawyers and doctors."⁷

Sometimes doctors are also good at telling stories, of course, and when bioethics scholars turn their attention to nonfiction it is usually to the work of physicians who are also well-known writers, including Richard Selzer, Oliver Sacks, Sherwin Nuland, Jerome Groopman, and Atul Gawande.⁸ There is also an occasional mention of nonfiction work by writers who are not physicians, such as poet Audre Lorde's illness memoir *The Cancer Journals*. But missing from the discussion has been recognition that professional journalists might also produce work that is worthy of scholarly consideration.

An Overlooked Genre

Although journalism, in general, has not received much careful analysis within bioethics, literary journalism in particular has been largely ignored. The genre seems to have fallen into a gap between bioethics's interest in literature and its critique of the news media. There is irony in

this because literary journalism may offer one of the most hopeful sites for bioethicists to engage with journalism in ways that are meaningful and productive rather than irritating and distressing. One reason is that this form of journalism stands as a distinct alternative to the standard models of mainstream journalism that many bioethicists find so frustrating and inadequate. In fact, literary journalists often share the same concerns as bioethicists about “sound-bite journalism” driven by the constraints of tight deadlines and rigid news-writing conventions; they are trying to do journalism in a different way. For example, writers in this genre often try to immerse themselves in their subjects’s lives and explore the full complexity of the issues and situations they face. Therefore, when literary journalists seek to interact with bioethicists, it is not likely to be for the purpose of extracting a sound bite that can be plugged into a story but rather to deepen the journalist’s own understanding—and the reader’s—about a complicated issue. If bioethics has a stake in raising the level of public discourse on ethical issues in science and medicine, scholars in the field need to recognize that literary journalism offers important opportunities for that to occur.

An additional reason that bioethics scholars would benefit from taking literary journalism more seriously is that writing in this genre could provide useful data for their own field. Through immersion reporting, literary journalists often witness—and write about—intimate interactions between patients and their families and health care providers. Journalists spend months, even years, immersing themselves in their subjects’s daily lives, in an effort, as Mark Kramer has written, “to comprehend subjects at a level Henry James termed ‘felt life’—the frank, unidealized level that includes individual difference, frailty, tenderness, nastiness, vanity, generosity, pomposity, humility, all in proper proportion.”⁹ Bioethicists, however, typically do not immerse themselves in patients’s lives; it is not among their methods. In fact, their direct contact with patients may be quite limited in comparison to journalists whose immersion reporting puts them not only at the patient’s hospital bedside, but also in patients’s homes, in their communities, and among their family members and friends. Many bioethics scholars have turned to literary fiction as one strategy for developing deeper insight into how people feel and behave when they or their loved ones experience illness, disability, and death. But some of the texts they have chosen for this purpose have inherent limitations. For all that nineteenth-century novels offer, for example, they cannot represent what it is like to be a patient or doctor in the twenty-first century. But literary journalism can. Journalists tell stories about real people, actual experiences, in specific contexts. Surely some of these stories are worthy of examination and reflection within bioethics.

In the next section, I briefly discuss three books of literary journalism that deal directly with bioethics concerns. These are books that scholars in bioethics, and in related fields such as medicine, nursing, and public health, are likely to be familiar with, and perhaps even to have read. But they are not likely to recognize these books as all belonging to the genre of literary journalism.

Three Books for Bioethics

Among contemporary book-length works of literary journalism that have taken up issues related to medical ethics and practice, one of the most well known is Anne Fadiman's book *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, published in 1997. Fadiman's book tells the story of a "collision" in the 1980s between a Hmong family, the Lees, who had recently arrived in the United States from Laos, and doctors at a hospital in California who tried to treat the Lees's young daughter, Lia, for recurring seizures. Lia's parents believed that when she was three years old her soul was so frightened by the sound of a door slamming that it fled her body and became lost. Lia's parents, Fadiman wrote, "recognized the resulting symptoms as *qang dab peg*, which means 'the spirit catches you and you fall down.'"¹⁰ But her doctors diagnosed her condition as epilepsy, which began a series of conflicts with Lia's parents over the nature of her illness and its appropriate treatment. As Fadiman's book describes, Lia's doctors treated her illness the best they could, but they spent little time trying to understand the Lees's perspective on their daughter's condition.

Fadiman spent eight years researching and writing *The Spirit Catches You*, during which time she burrowed into the Lees's daily lives. One result of this long immersion was that Fadiman formed a deep attachment to the Lee family. In a public lecture at the University of Minnesota in 2009, more than a decade after her book was published, she said she still remained in regular contact with the Lees, who continued to care for Lia at home.¹¹

Fadiman's account of cross-cultural misunderstanding won the National Book Critics Circle Award for general nonfiction in 1998 and has received significant attention within schools of medicine, nursing, public health, and social work. The book is widely assigned in courses on cross-cultural medicine and medical ethics, and has been required reading for first-year students at several medical schools.¹² So, although the bioethics discourse on literature has focused mainly on fiction and physician-authored essays and memoirs, one of the most important literary texts used in academic health centers's curricula in recent years has actually been the work of a journalist.

Another book that has been widely read and discussed in medical and health circles is Tracy Kidder's *Mountains Beyond Mountains: The Quest of Dr. Paul Farmer, a Man Who Would Cure the World*, published in 2003. Kidder's book offers an intimate portrait of Paul Farmer, a physician and medical anthropologist who cofounded the international nonprofit organization Partners in Health, which is dedicated to improving health care for poor people in the developing world. Kidder's book describes the trajectory of Farmer's life, from growing up in a large family that lived at times in a trailer park, on a bus, and on a boat that lacked running water, to graduating from Harvard Medical School and opening a clinic in rural Haiti. Farmer has become an influential figure in global public health, particularly in the effort to combat HIV and multidrug-resistant tuberculosis. Like Fadiman, Kidder spent a considerable amount of time with his subject in order to write *Mountains Beyond Mountains*. This included long periods spent observing Farmer with patients at his clinic in Haiti, on rounds at Brigham and Women's Hospital in Boston, and on trips to Russia, Cuba, France, and Peru. In the end, Farmer comes across as charismatic, complex, and intensely committed to treating the sickest patients in the world's poorest nations. The reader is left to wonder what health care might be like if more medical professionals embraced Farmer's philosophy of focusing energy and resources on patients with the greatest needs.

A third book of literary journalism, one that has recently attracted significant interest from both general readers and scholars, is *The Immortal Life of Henrietta Lacks*, authored by Rebecca Skloot and published in 2010. Skloot's book weaves several overlapping stories into a seamless narrative that one reviewer, a cell biologist writing in *The Journal of Clinical Investigations*, has described as "an unforgettable story that reads like a novel."¹³ Among the stories the book recounts is the short life of Henrietta Lacks, an African-American woman born in 1920 and raised on the same tobacco farm in Virginia that her ancestors had worked as slaves. Lacks dropped out of school in sixth grade to work in the fields and gave birth to her first child at the age of fourteen. She died seventeen years later, from an aggressive form of cervical cancer, in the "colored ward" of Johns Hopkins Hospital in Baltimore. Before she died, however, doctors took tissue samples from her cervix, without her consent, and placed them in a Petri dish. These extraordinary cells, known as "HeLa" cells, were the first human cells to survive and multiply in culture. The cells proved so hardy, in fact, that medical researchers have used them in thousands of studies throughout the past sixty years, making them one of the most important, and lucrative, cell lines in the history of biomedical research. However, Lacks's own children,

growing up in Baltimore, had no idea their mother's tissue had been taken and used for research. Much of Skloot's book is devoted to the story of the Lacks children and how their lives were affected first by their mother's death and then by discovering years later that her cells had been transformed into a valuable commodity without their knowledge and without any financial compensation provided to the family.

Skloot, a science journalist who has taught creative writing and journalism at several universities, spent more than a decade researching and writing the book. Among the most extraordinary aspects of her work was her determination to forge relationships with Henrietta Lacks's grown children, who, for good reason, had become suspicious of people coming around asking questions about their mother. Skloot formed a particularly close bond with Henrietta's only surviving daughter, Deborah, who was a baby when her mother died and whose lifelong struggles are described with great empathy. In addition, Skloot has directly linked the story of Henrietta Lacks, her children, and her "immortal" cells to the history of bioethics as a movement that emerged largely in response to public concerns about the exploitation of human subjects in medical research.

All three of these books offer important contributions to public discourse about ethics in medicine. They are also powerful narratives that incorporate the "shared characteristics" of literary journalism summarized by Norman Sims as "immersion reporting, complicated structures, character development, symbolism, voice, a focus on ordinary people . . . and accuracy."¹⁴ But books such as these are not the only form in which literary journalism can be found. In the next section, I discuss two examples of long-form narratives published by newspapers that also provide insight into important aspects of patients's lives, their experiences of illness and medical treatment, and the difficult dilemmas they encounter.

Newspaper Narratives

In recent years a number of major daily newspapers around the country have devoted significant space within their pages and on their websites to publishing long-form narratives, sometimes as multi-part series that run over a period of several days or even weeks. A notable example is a series called "Through Hell and High Water," which appeared in the *Atlanta Journal-Constitution* in May 2006. Published in twenty-two daily chapters, the series offered a detailed account of the horrific experiences that patients and medical staff endured at two New Orleans hospitals—one public, one private—after the hospitals lost power during Hurricane Katrina.¹⁵

Among the themes that newspaper narratives have examined is the difficult decision making that often confronts very sick patients and their

families. A case in point is a series the *Cleveland Plain Dealer* published in November 2006. The four-part narrative focused on Dakota Bihn, a six-year-old girl with Tay-Sachs disease, which is a rare genetic disorder that affects the central nervous system.¹⁶ As the series describes, a neurologist at the Cleveland Clinic who diagnosed Dakota's illness told her parents there was no effective treatment and that Dakota would likely not live past the age of fifteen. Dakota's parents, unwilling to accept such a prognosis, found a prominent hematologist at Duke University Medical Center who offered to perform an experimental treatment on their daughter, an umbilical cord-blood transplant. Dakota's neurologist recommended against the transplant due to lack of evidence that it would be effective and because the complications, he told her parents, were likely to be painful. Nonetheless, Dakota's parents decided she would undergo the procedure.

One aspect of this series that is particularly important from a bioethics standpoint is that it offers a vivid portrait of parental desperation. When the Bihns were told their young daughter had a fatal illness with no known cure, that information overrode any other factor in their decision to try an experimental treatment. But as the series shows, the Bihns's optimism before the transplant turned to anguish and frustration soon afterward, as they watched their daughter's condition deteriorate rather than improve. Here is the beginning of part one in the series:

Julie Bihn watched helplessly as her 6-year-old daughter, Dakota, lay in her hospital bed, repeatedly digging her nails deep into her skin. Dakota was covered head to toe with a rash that triggered an unbearable itch. It was the latest side effect to erupt from an unorthodox treatment for her fatal disease.

Three months earlier, the kindergartner had been skipping down the halls of Falls-Lenox Primary School, her pink "Dora the Explorer" backpack and her long, blond pigtails bouncing, giggling with friends and repeating funny lines from the movie "Ice Age." Now, Julie couldn't remember the last time she had seen her daughter's blue eyes open.¹⁷

By centering the story on the parents's point of view and their love for their daughter, this narrative works on an emotional level to explain how parents can be convinced to try an unproven treatment for their seriously ill child, even when most doctors would advise against it. It would be difficult to find a topic more relevant to bioethics than the profound difficulties involved in weighing the risks and benefits of an experimental treatment, particularly for one's own child.

A second aspect of this series worth noting is that it illustrates how the informed consent process—considered a critical step before any medical

treatment—can become all but meaningless in situations where parents are so desperate they choose to ignore potential downsides. Part three in the series reconstructs how the informed consent process worked (or rather *didn't* work) for Dakota's parents:

Ken and Julie were eager to get Dakota's transplant started when a nurse asked them to sign the consent form.

Informed consent is an important part of any medical procedure. There's no reality check like seeing the hard road ahead spelled out in black and white.

Dakota's consent form was nine pages. The cord-blood transplant is a treatment plan for an inherited metabolic disorder, the form said. Tay-Sachs wasn't specifically mentioned. [Ken] said he skimmed the rest, signed it and handed it to Julie.

She said she signed it without reading any of it.¹⁸

But it wasn't long before Ken and Julie began to wonder if they had made the right decision. Two days after the transplant, Dakota "was vomiting blood nonstop and couldn't get out of bed." Fifty days later, she could no longer eat or walk and could hardly speak. She had lost her hair and was covered in a painful rash, both side effects of the treatment. Six months after the transplant, Dakota was in so much pain she would not let even her mother hold her. Finally, a year after the transplant, Dakota turned a corner and became well enough to live at home again. But her parents had dramatically lowered their expectations about her long-term prognosis and her mother expressed doubts about whether, all things considered, they had made the right decision.¹⁹

Reporter Diana Keogh spent eleven months researching and writing the series. This is a length of time not often afforded newspapers journalists, but it allowed Keogh to immerse herself in the Bihns's daily lives and to capture scenes that deepen the reader's understanding of the decisions made by Dakota's parents.

A similar example is a six-part narrative published by the *Boston Globe* in 1999.²⁰ The series tells the story of a young couple, Greg Fairchild and Tierney Temple-Fairchild, who found out from an ultrasound test and amniocentesis that the baby they were expecting had a severe heart defect as well as Down syndrome. The couple agonized over whether to terminate the pregnancy, which some friends and family members urged them to do. As the story explains, the results of prenatal screening can sometimes present a profound dilemma for prospective parents:

Most disorders tested for today—including Down syndrome, muscular

dystrophy, and cystic fibrosis—cannot be corrected. That means the most common question prompted by distressing prenatal test results is not, “How can we fix it?” It is: “Should this pregnancy continue?”

Those questions are growing rapidly for countless couples who, like Tierney and Greg, would consider abortion under certain circumstances.²¹

In this case, the parents ultimately decided to continue the pregnancy, which resulted in the birth of their daughter, Naia. But it was not an easy decision. Tierney and Greg went back and forth several times about what to do. In this scene, when they finally made their decision, they had already talked through all of the factors involved:

But when there are no more words left to say, it doesn't add up to abortion. They look at each other and know they have decided: They will have this baby.

They call it a leap of faith.

“If I had to terminate, I could bring myself to do it,” Tierney tells Greg through tears. “But to terminate in a circumstance where I was afraid of taking on a challenge, I just don't think I could live with the repercussions it would have on my life. On our life together.

“Why wouldn't I allow God to take this pregnancy where it needs to go? And if my baby is going to die in heart surgery, my baby is going to die in heart surgery. My dad might say, ‘Tierney, why do you have to go through that, or why does your baby have to go through that pain?’ But I have to trust.”²²

Reporter Mitchell Zuckoff later expanded the series into a book, called *Choosing Naia: A Family's Journey*, published in 2002.

Newspaper narrative series about illness and medical treatment, birth and death, are not altogether rare. Some even win awards. The first Pulitzer Prize for Feature Writing, awarded in 1979, went to Jon D. Franklin at the old Baltimore *Evening Sun* for a story called “Mrs. Kelly's Monster,” which described a high-risk surgery to remove a tumor from a woman's brain.²³ More recently, Tom Hallman, Jr., at *The Oregonian* won the Pulitzer Prize for Feature Writing in 2001 for “The Boy Behind the Mask,” a four-part series about a teenage boy named Sam who was born with a congenital disfigurement and chose to undergo surgery that would give him a more normal face.²⁴ The series was later expanded and published in book form. Despite such recognition, even the most compelling newspaper stories about real people's actual experiences of illness, disability, and death have gone unmentioned, and probably for the most part unnoticed, within bioethics. If this continues, it will be a significant missed opportunity for a field that attempts to understand moral issues within their specific context.

Establishing New Connections

When literature and journalism are conceptualized as two distinct categories that are poles apart, it is not hard to understand how literary journalism often gets overlooked within the academy. Literary scholars can comfortably assume that any writing that qualifies as “journalism” must be outside the scope of their concern, while scholars who critique the news media can focus their attention on more obvious targets, such as network television news programs. But literary journalism cannot remain a blind spot for bioethics, if for no other reason than because this form of writing can be just as illuminating about the human condition as literary fiction. If we acquire moral knowledge from stories written by novelists and playwrights, as literary scholars have claimed, this should be no less true of stories about real people written by literary journalists.

Recently, there have been hopeful signs that bioethics may be shifting toward greater awareness and appreciation of literary journalism. One sign is the warm response to Rebecca Skloot’s book *The Immortal Life of Henrietta Lacks*. One place this response can be seen is a recent issue of the *Hastings Center Report*. For its July/August 2010 issue, the journal asked several writers in the field to contribute an essay “on a book or books exploring bioethics through story.”²⁵ Three of the four essays published discussed only works of fiction: Kazuo Ishiguro’s *Never Let Me Go*, Anthony Trollope’s *Doctor Thorne*, Ken Kesey’s *One Flew Over the Cuckoo’s Nest*, and three novels by Jodi Picoult. However, one essay examined a work of nonfiction: Skloot’s *Immortal Life*. The author of the essay, physician John D. Lantos, compared Skloot’s book to Richard Powers’s 2009 novel *Generosity: An Enhancement* about a young Algerian woman who escapes the brutality in her home country and becomes a remarkably well-adjusted college student in the United States. The woman’s emotional resilience draws the interest of a scientist who is trying to find the genetic basis for happiness. Significantly, Lantos asserted that the two books—Skloot’s *Immortal Life* and Powers’s *Generosity*—share important themes:

Both books—the true story and the novel—are about unassuming innocents who fall into the clutches of biomedical researchers.... Both books weave together stories about deprivation and poverty with stories about science as the ultimate redemption story of our age.... Both struggle with the fundamental bioethical questions of the genomic age—whether we will be able to unlock the secrets of cancer, cystic fibrosis, or happiness without destroying ourselves in the process.²⁶

The same issue of the *Hastings Center Report* also included a review of Skloot’s book that called it “a luminous, transfiguring, and true story of a

journalist's quest to learn about the woman whose cancerous cervical tissue became HeLa, the first line of immortal human cells.²⁷ Similarly positive reviews have appeared in recent issues of journals such as *Health Affairs*, the *Journal of Clinical Investigation*, and *Issues in Science and Technology*, which may indicate that Skloot's book has broken through and achieved a level of interest and admiration rarely bestowed on works of literary journalism. For that reason, the book could offer a timely bridge for creating new connections between bioethics and this form of journalism.

An additional opportunity may be found in the recently published writings of a philosopher and bioethics scholar, Carl Elliott, of the University of Minnesota. *The New Yorker* magazine has published two articles by Elliott in the past two years, both of which employ narrative techniques typically found in literary journalism, including scene setting, dialogue, and the distinctive voice of a narrator.²⁸ Although other scholars in the field of bioethics have yet to follow Elliott's lead, more could decide to incorporate the techniques and methods of literary journalism into their own writing in an effort to reach a broader audience.

An additional sign that there may be expanding opportunities to develop connections between literary journalism and bioethics is that some scholars in bioethics seem to be reassessing their stance toward journalism and the media. James Lindemann Nelson, a philosopher at Michigan State University who works primarily in bioethics, observed more than a decade ago that bioethicists who tend to disparage journalism actually lack empirical information on which to judge whether engaging with the press is practically useful or morally legitimate. He wrote,

We don't know who pays attention to what bioethicists say in the press, what they understand by what they hear, and how such encounters affect people's thinking, either about the specific issue in question, or about broader matters, such as how to reason about ethical issues in general, or which forms of authority are appropriate in moral discussion and which are not.²⁹

Picking up on this theme, Tod Chambers, a professor of medical humanities and bioethics at Northwestern University, recently called for "expanded media literacy for bioethicists."³⁰ If there is movement in this direction within bioethics, hopefully scholars in the field will recognize that literary journalism offers significant opportunities for more productive engagement with journalists and journalism scholars, including even collaboration. Scholars of literary journalism, from their perspective, might try to look for such cross-disciplinary opportunities as well.

Amy Snow Landa is a doctoral student in the School of Journalism and Mass Communication at the University of Minnesota. She is co-teaching a course with Carl Elliott this semester called "Investigative Journalism and Bioethics." It may be the first course offered by a U.S. university that combines "journalism" and "bioethics" in the title.



Endnotes

¹ Kathryn Montgomery, "Literature, Literary Studies, and Medical Ethics: The Interdisciplinary Question," *Hastings Center Report* 31, no. 3 (2001): 36.

² Peter Simonson, "Bioethics and the Rituals of Media," *Hastings Center Report* 22, no. 1 (2002): 34.

³ *Ibid.*, 32.

⁴ Examples in addition to those cited by Simonson in "Bioethics and the Rituals of Media" include Steven H. Miles, "Medical Ethicists, Human Curiosities, and the New Media Midway," *American Journal of Bioethics* 4, no. 3 (2004): 39–43; Arthur L. Caplan and Joseph Turow, "Taken to Extremes: Newspapers and Kevorkian's Televised Euthanasia Incident," in *Cultural Sutures: Medicine and the Media*, ed. Lester D. Friedman (Durham, N.C.: Duke University Press, 2004), pp. 36–54; Judith Andre, Leonard Fleck, and Tom Tomlinson, "Improving Our Aim," *Journal of Medicine and Philosophy* 24, no. 2 (1999): 130–147; Martyn Evans, "Bioethics and the Newspapers," *Journal of Medicine and Philosophy* 24, no. 2 (1999): 164–180; and Leigh Turner, "The Media and the Ethics of Cloning," *Chronicle of Higher Education*, 26 September 1997: B4–B5.

⁵ Montgomery, 36.

⁶ Examples include Arnold J. Rosin, "George Eliot's *Middlemarch*: A Contribution to Medical Professionalism," *Medical Humanities* 35 (2009): 43–46; Fred Butzen, "Chekhov's Doctors: A Collection of Chekhov's Medical Tales," *Journal of the American Medical Association* 291, no. 15 (2004): 1905–1906; Carl Elliott and John D. Lantos, eds., *The Last Physician: Walker Percy & the Moral Life of Medicine* (Durham, N.C.: Duke University Press, 1999); Karl A. Lorenz, M. Jillisa Steckart, Kenneth E. Rosenfeld, "End-of-Life Education Using the Dramatic Arts: The Wit Educational Initiative," *Academic Medicine* 79, no. 5 (2004): 481–486; Rita Charon, "The Ethical Dimensions of Literature: Henry James's *The Wings of the Dove*," in *Stories and Their Limits: Narrative Approaches to Bioethics*, ed. Hilde Lindemann Nelson (New York: Routledge, 1997), 91–112; and Charles Weijer, "Film and Narrative in Bioethics:

Akira Kurosawa's *Ikiru*," in *Stories and Their Limits: Narrative Approaches to Bioethics*, ed. Hilde Lindemann Nelson (New York: Routledge, 1997), 113–122.

⁷ Carl Elliott, *A Philosophical Disease: Bioethics, Culture, and Identity* (New York: Routledge, 1999), xxvi.

⁸ For example, in her essay "Literature, Literary Studies, and Medical Ethics," Montgomery mentions Richard Selzer, Sherwin Nuland, and Jerome Groopman among the physician-authors who have "revealed the texture of medical practice." See Montgomery, p. 36.

⁹ Mark Kramer, "Breakable Rules for Literary Journalists," in *Literary Journalism: A New Collection of the Best American Nonfiction*, ed. Norman Sims and Mark Kramer (New York: Ballantine Books, 1995), 23.

¹⁰ Anne Fadiman, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures* (New York: Farrar, Straus and Giroux, 1997), 20.

¹¹ Author's notes, "An Evening with Author Anne Fadiman," March 2, 2009, Magraw-Fuller Lecture Series, University of Minnesota, Minneapolis.

¹² Janelle S. Taylor, "The Story Catches You and You Fall Down: Tragedy, Ethnography, and Cultural Competence," *Medical Anthropology Quarterly* 17, no. 2 (2003): 159–181.

¹³ Stacie Bloom, "The Immortal Life of Henrietta Lacks (Book Review)," *Journal of Clinical Investigation* 120, no. 7 (July 2010): 2252.

¹⁴ Norman Sims, *True Stories: A Century of Literary Journalism*. (Evanston, Ill.: Northwestern University Press, 2007), 6–7.

¹⁵ Jane O. Hansen, "Through Hell and High Water," *Atlanta Journal-Constitution*, 5–27 May 2006. <<http://www.ajc.com/blogs/content/shared-blogs/ajc/twohospitals>>. Retrieved 20 September 2010.

¹⁶ Diana Keough, "Tay-Sachs: At What Cost?" *Cleveland Plain Dealer*, 5–8 November 2006. <<http://www.cleveland.com/taysachs>>. Retrieved 20 September 2010.

¹⁷ Keough, "At What Cost?" *Cleveland Plain Dealer*, 5 November 2006. <<http://www.cleveland.com/taysachs/plaindealer/index.ssf?/taysachs/more/116257140714160.html>>. Retrieved 20 September 2010.

¹⁸ Keough, "A Family's Hopeful Trip Down an Unproven Road," *Cleveland Plain Dealer*, 6 November 2006. <<http://www.cleveland.com/taysachs/plaindealer/index.ssf?/taysachs/more/1162729818203320.html>>. Retrieved 20 September 2010.

¹⁹ Keough, "Life and Death After Transplants," *Cleveland Plain Dealer*, 8 November 2006. <<http://www.cleveland.com/taysachs/plaindealer/index.ssf?/taysachs/more/116293770349350.html>>. Retrieved 20 September 2010.

²⁰ Mitchell Zuckoff, "Choosing Naia: A Family's Journey," *Boston Globe*, 5–10 December 1999. <<http://cache.boston.com/globe/nation/packages/naia>>. Retrieved 20 September 2010.

²¹ Zuckoff, "A Hole in the Heart," *Boston Globe*, 5 December 1999. <<http://cache.boston.com/globe/nation/packages/naia>>. Retrieved 20 September 2010.

²² Zuckoff, "Reaching a Decision," *Boston Globe*, 6 December 1999. <<http://>

cache.boston.com/globe/nation/packages/naia/part2.htm>. Retrieved 20 September 2010.

²³ “Mrs. Kelly’s Monster” is included in *Intimate Journalism: The Art and Craft of Reporting Everyday Life*, ed. Walt Harrington (Thousand Oaks, CA: Sage Publications, 1997), 97–106.

²⁴ Tom Hallman, Jr., “The Boy Behind the Mask,” *Oregonian*, 30 September, 2–4 October 2000. <<http://www.oregonlive.com/mask>>. Retrieved 20 September 2010.

²⁵ *Hastings Center Report* 40, no. 4 (July/August 2010): 16.

²⁶ John D. Lantos, “A Better Life through Science?” *Hastings Center Report* 40, no. 4 (2010): 22–25.

²⁷ Virginia A. Sharpe, “One Life, Many Stories,” *Hastings Center Report* 40, no. 4 (2010): 46–47.

²⁸ Carl Elliott, “Guinea-pigging,” *New Yorker*, 7 January 2008: 36–41; Carl Elliott, “Mind Game,” *New Yorker*, 6 September 2010: 36–43.

²⁹ James Lindemann Nelson, “Bioethics as Several Kinds of Writing,” *Journal of Medicine and Philosophy* 24, no. 2 (1999): 148–163.

³⁰ Tod Chambers, “It’s Narrative All the Way Down,” *American Journal of Bioethics* 7, no. 8 (2007): 15–16.