

When Your Body Stops Being You

Hollywood and its media representations often define public perception. Individuals with Parkinson's disease rarely find accurate portrayals of their lives in movies or on TV. Dr. Jenny Nelson and her apprentice Stephen Toropov are studying how those with Parkinson's then manage their identities in the online world.

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By Rachel Grimm
Photos by Paula Welling



When Dr. Jenny Nelson was initially diagnosed with Parkinson's disease in 2010, she decided to get informed about her disease and her options. But the more she researched, the more she felt that "there was something not [quite] right" in the stories she saw in the media. With the help of Stephen Toropov, a sophomore studying English, Nelson is studying the media narratives surrounding Parkinson's in an effort to understand the media's effect on how those living with the disease articulate their personal experiences.

Representations of Parkinson's in the media can be summed up by an episode of the television medical drama "House," Nelson explained. When Dr. House informs his patient that she might have Parkinson's, she responds with a gasp that she would rather have cancer.

In the media, a diagnosis of Parkinson's is a death sentence, a sort of "neurological boogie man," Stephen said. "[It's] a disease that nobody really wants to watch." When the media depicts people with Parkinson's—especially in advanced stages—it is in scenes that are meant to shock the audience. In one such scene in the movie "Love and Other Drugs," the protagonist, recently diagnosed with Parkinson's, sits in a trembling audience of Parkinson's patients and listens to her peers rattle off a laundry list of the mundane complications plaguing their everyday lives. "F*** soup," one character exclaimed.

The list of daily struggles is endless and includes: shoe laces, jewelry, brushing teeth, tying a tie, buttoning a shirt and holding a baby. In advanced stages, Parkinson's affects even the most basic motor skills, bodily functions and mental faculties. "It's not a disease—it's a Russian novel," said the husband of one woman in "Love and Other Drugs" who suffers from advanced Parkinson's disease.

"These images . . . sort of impede your future," Nelson said. "Is this a misrepresentation in the same way that I know women are misrepresented ... that blacks are misrepresented?"



Left: Dr. Jenny Nelson, Media Arts & Studies
Right: Stephen Toropov, English

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The representations we see in the media—of gender, of race and even of disease—tend to reflect the dominant ideologies and institutions of a given society. Representations of Parkinson's in the media are the collective visualization of pharmaceutical corporations, medical institutions and insurance companies, Nelson said.

In the 1970s, when medical shows first came into vogue, doctors were seen as "gods in white coats," Nelson said. And while contemporary medical shows like "House" and "Scrubs" have begun portraying doctors as flawed characters, they still end up as heroes. But it's hard to fit the hero mold when a doctor diagnoses a patient with a disease like Parkinson's that simply cannot be cured at the end of the hour, she said.

For Nelson, one notable consequence of Parkinson's media depiction appears within the therapy profession. Because Parkinson's requires persistent palliative care—treatment or therapy that helps to relieve pain but does not cure its underlying causes—there is a "perceived non-reward," she explained. Medical professionals want to help their patients get well, but "with Parkinson's, you just see a slow decline," Nelson said, laughing a bit grimly before she added, "'caretaker' sounds like such a funeral."

But while the medical community and the media continue to treat Parkinson's as a taboo, Stephen is a bit more hopeful.

"There is more and more hope for finding ways to manage and to cure Parkinson's," Stephen said. "If the only literature that is out there about this disease is this impenetrable wall of statistics and medical jargon, and it's never looking at what someone who actually has Parkinson's experiences . . . it's going to adversely affect [the] quality of life aspect."

As opposed to television representation, literature on Parkinson's can be broken up into four main subsets: medical journals, health manuals, motivational literature and stories about the inevitable "end of the road," Nelson said.

"I read one book that scared the shit outta me," she admitted. "Is that gonna be me?"

With no significant media representation, Parkinson's patients are instead reaching out to one another through online forums that invite people to share their stories. Nelson and Stephen want to see how Parkinson's patients are presenting their own narratives despite a seemingly unreceptive media. Stephen's background in narratology—the study of narrative structure and function—has proved invaluable for this aspect of the research project.

Thus far, Nelson and Stephen have looked at three online forums. Already, they have noticed significant differences among the three sites of interest. While the European Parkinson's Disease Association features a modern, easily navigated, and welcoming site, the American site pales in comparison. But Nelson's favorite site thus far is Patient Commando, which, in her opinion, rescues patients' personal experiences from the jargon of the medical community and the negativity of the media.

Nelson and Stephen are interested in analyzing just how Parkinson's patients share their stories, and what social roles they assume within the micro-communities of the online forums. An equal part of Nelson and Stephen's research involves looking at actor Michael J. Fox's public Parkinson's narrative.

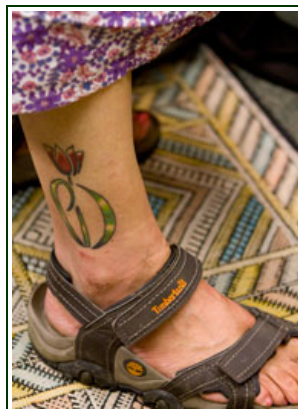
Diagnosed with Parkinson's in 1991, Fox has, in Nelson's opinion "single-handedly given Parkinson's . . . a much wider appeal and a wider range of visibility." And while Fox has been tireless in raising funds and awareness for Parkinson's research, his position as the spokesperson for the disease is, in a word, problematic.

"We're interested in the way that he performs as himself, or as other characters in shows . . . His disease is visible . . . [but] he never calls it Parkinson's," Nelson said. When she watches Fox's appearances in the media, she can't help but ask herself, "How much is he willing to give away? How bad is it, brother?"

For Stephen, an aspiring creative writer, the question always comes back to narrative. "What does it mean to talk about having a serious disease?" he said. "What does it mean to have your body not be under your control. What happens when the reality of what your body is doing stops meeting the story you tell yourself about who you are?"

Everyone tells themselves a story about who they are, Stephen explains, and the body is the primary vehicle for the performance of this identity narrative. What happens, then, "when your body stops being you?"

Nelson, too, tells a story. A Fulbright recipient, an international scholar, and a breast cancer survivor, Nelson's life story has been replete with ambition and success. On her right ankle, she has tattooed the European symbol for Parkinson's. A green "P"



and "D" wrap around one another like two hands cupped, and out of this embrace, a red tulip blooms.

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