

Issue 10

# ATRIUM

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The Report of the Northwestern Medical Humanities and Bioethics Program

*Graphic*



"Dissection of it All," photo by Diana Eastman

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## About the Cover

Graphic representations are always specially valuable to the reader.

—SCIENCE 3 (1884): 164.

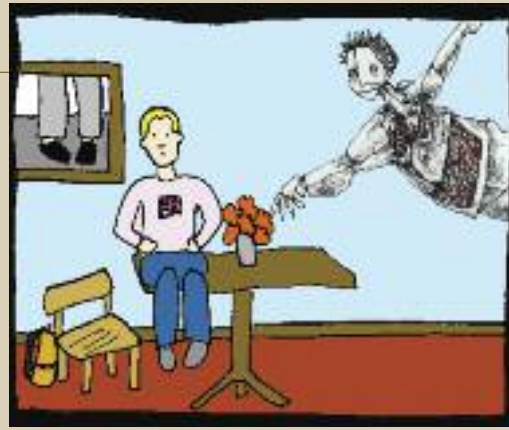
Strictly speaking, the word *graphic* means *that which is drawn*: a visual representation. It can also mean something described in words so vividly that it leaps into the reader's imagination as if seen directly, all at once, with the eyes. Complex data is drawn on a graph so that, instead of calculating what is more and what less, we see at a glance that one bar is longer or one slice is smaller. The graphic does not *tell*, it *shows*.

Unsurprisingly, then, the word *graphic* has come to be associated with things we prefer to keep covered or mediated with protective words. These things most often concern our bodies: graphic warning labels on cigarette boxes show us filthy tumorous lungs; ads for explicit horror films tell us the squeamish will be upset. Polite manners dictate against use of graphic language, specifically words that conjure vivid visual images whose presence is not welcome in polite situations. Often these are the things revealed by “graphic sex and violence”: the things we usually keep covered, by our clothes and by our skin, our private parts and internal organs.

These are also the things that concern medicine. Consider the hospital gown. The body must be uncovered to be examined, its insides imaged to be diagnosed, dissected to be understood. Physicians learn not to find such access disturbing. Patients may eventually learn not to feel too impolitely exposed by the stirrups or the scan. And graphic attention to our bodies, uncomfortable as it may make us, can also remind us of the body's complex meanings more powerfully than the most comprehensive information or the most specific written narrative.

Graphic narratives about disease, and about being ill and caring for the ill, are becoming widely recognized for telling—and showing—aspects of the health care experience that other media cannot. A new field, *Graphic Medicine*, seeks to promote the reading and making of comics in the medical context.

The graphic is ambiguous. It can repel us. But because it is essentially about representation—the making of images, whether



with words or lines, of something we may not otherwise see—it is also inherently about art. The graphic is always concerned with the aesthetic, the effects an artist intends an image to have

on its viewer: to disturb, to outrage, to move, to disarm with awe.

Or, like the image on our cover, to fix our attention with the wonder of something beautiful, the play of light on skin, and the reminder that under this limpid membrane is life. This image, a nude, is graphic in that the inside of her body is superimposed—*drawn*—onto the outside of the model's body, delicately yet accurately revealing the internal structures yet not doing any harm. Notice that you can see more on her skin than just musculature and bone. The anatomist—Henry Gray, for the drawing is from his famous 19th-century anatomy manual—did not only copy what he found in the cadaver he'd dissected. He included what medicine always adds to nature: the naming of parts, the labels and signs with which medicine sorts out the immense material of human anatomy. Trapezius, rhomboid, the chain of vertebrae, are all neatly numbered in copperplate.

Perhaps this is an ideal of medical knowledge: to understand the individual human body, inside and out, without threatening the integrity either of the body or the person who inhabits it. Maybe this is what the graphic is for.

Catherine Belling and MK Czerwiec  
Guest co-editors, Atrium 10

Cover Photo: “Dissection of it All,” by Diana Eastman  
[www.deeastman.com/](http://www.deeastman.com/)

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Tod Chambers, PhD—Associate Professor of MH&B and of Medicine; Director of MH&B  
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Debjani Mukherjee, PhD—Assistant Professor of Physical Medicine & Rehabilitation and of MH&B; Director, Rehabilitation Institute of Chicago Donnelly Ethics Program; Assistant Director of Graduate Studies, MH&B  
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Myria Knox—Program Assistant  
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# The View From the Spectrum:

## The Challenges of Picturing Autism in Comic Form

Courtney Angermeier and Jeff Benham

About four years ago, after attending a conference on autism, we had an idea for a short comic. We have been working on that idea, now a graphic novel titled *Peoplings*, for over three years. It is a piece about autism and the roots of special education, which we are initially publishing in three volumes.

*Peoplings* follows two parallel storylines, both based on true stories. The first storyline is about Max, a contemporary boy with autism. Max's story is based on a friend of ours, his family, and his treatment team. The second story follows Victor D'Aveyron, a historical case of severe isolation from early 19th century France.



All images © 2011 Courtney Angermeier and Jeff Benham.

**Image 1: Max in Kindergarten**—*Peoplings* follows two parallel storylines. The first is about Max, a contemporary boy with autism.



**Image 2: Victor and Itard**—The second story follows Victor D'Aveyron, a well-known feral child found in France in 1800.

(continued on next page)



**Image 3: First Diagnosis Page**—In the first draft of the scene where Max is diagnosed with autism we wanted to show both Max's parents' and Max's perspective at the same time.

Both Max and Victor's development as individuals is profoundly affected by their interactions with the medical establishments of their time. Dr. Jean-Marc Gaspard Itard worked with Victor for the better part of six years and, in this work, developed techniques that were extremely influential in the evolution of special education and the subsequent treatment of autism. Through the course of Max's diagnosis and treatment, readers can see the development and standardization of these techniques as well as dramatic social changes in the relationships between doctors and patients and in the understanding of the situated nature of disability. Max's story approaches the notions of ability and disability mostly from a social perspective, leaning heavily on the idea that disability and disease are constructs of particular settings. Victor's story, on the other hand, comes more from a traditional medical perspective in which disability is a patient-contained pathology. In *Peoplings*, we wanted to tell these two boys' stories as well as show the complicated relationship between these two perspectives, both historically and in contemporary society. In addition, we wanted to include some visual representation of Victor and Max's experiences and perceptions of reality.

Developing a visual representation of a non-neurotypical perspective is complex on many levels. The voices of individuals with neurological differences are frequently left out of public discourse. As neurotypicals ourselves, it is not our intent to co-opt these non-neurotypical voices. Rather, we hoped that, through presenting a version of what a non-neurotypical experience of the world might feel like, we might be able to assist in creating more space for these important voices to be heard. Through our relationships with loved ones on the autism spectrum, we have developed a deep appreciation of non-neurotypical ways of experiencing and interpreting the world. We wanted others to have access to these rich perspectives.

When we began this project, first-person narratives about autism were rare in a textual format and completely absent in graphic ones. If literature can be either a window or a mirror, this lack of aesthetic material about autism was distressing. Neurotypicals had only a small window into the experiences and perspectives of non-neurotypicals, and people on the spectrum, most importantly young people, had only a small mirror into which they could look and

find someone like themselves. Invested in supporting a body of work that could perform both of these functions, we hoped to develop a visual style that could represent these two boys' experiences of their worlds. We intend our visual representation of these two boys' experiences to be metaphorical rather than realistic. We are not trying to draw a picture of, say, what the world looks like to someone on the spectrum, but rather to draw a picture that might capture some of what being on the spectrum might feel like. We coined a word for this experiential style: "VI." The rest of this article will focus on how we have gone about developing Max's version of it.

At first, we thought VI would be a kind of looking-glass world in which Max and Victor were co-habitants... then we did more research. After interviewing individuals on the spectrum and their family members and therapists, and reading books and research and what memoirs on autism were available, we quickly came to realize that our initial concept of a fantasy-type world was completely off the mark. Individuals on the spectrum are intensely tied to the concrete world; it is the patterns and forms of reality interacting with their neurological differences that inform their unique experiences of the world, so any visual style that we created was going to have to have its basis in the elements (line, color, form) of "reality" as we defined it on the page. This meant that we first had to establish a base style for each story.

We wanted the two separate base styles to relate to the time period both aesthetically (in terms of common visual tropes of the time) and conceptually (in terms of the social constructs of disability). For Victor, we chose a flat-on visual perspective, working in direct planes reminiscent of Jacques-Louis David's (a contemporary of Victor's) compositional approach. This creates a kind of formal proscenium that readers must look through to access Victor's story, setting up a clinical distance for the reader that mirrors Victor's relationship to the medical establishment of his time. The images mimic two-toned woodcuts, as this was a common reproduction method for the period. For Max, the paneling is loose and lively. The panels themselves are far less formal, interacting in much the same way that multiple people interact with Max in his life and in his course of treatment. The line work has a clean, simple, modern style, utilizing contours, minimal details, and vibrant, unshaded colors.





**Image 4: Line Drawing of Final Draft**—After we had sorted out what the elements were, we made different choices about how to organize them within the conceptual framework.

Once we had defined these base styles, we set about trying to figure out how VI should look. Due in part to sensory integration issues and difficulty decoding social cues, individuals on the autism spectrum do not share neurotypicals' sense of what is "important" in any given environment. Their different systems of organizing information often lead to heightened pattern awareness and attention to detail. Inspired by our research (including information about eye-tracking in individuals on the spectrum) we wanted these ideas about focus and sensory input to be the driving principles for VI.

We wanted to show Max's intense focus on some objects, patterns, or experiences and his diffuse focus on others. Initially, we thought this might take the form of some things looking "more real" than the base style so we employed a rougher, more modeled, watercolor approach. This only succeeded in making Max's experience more real than that of the other characters in the story, without creating any insight into his perspective. Next, we played with Max having an awareness of the outlines of shapes and shadows that overlaid a more realistically depicted world. This was conceptually closer to our intent, but still didn't "feel" like the perspective we were trying to represent.

In the scene where Max is diagnosed with autism we wanted to show both Max's parents' and Max's perspective at the same time. Firstly, we wanted to unsettle the stable lines of the paneling style we had established as a means of communicating the destabilizing effect of Max's diagnosis on his parents; all their expectations about their child and their lives are upset by the diagnosis. We wanted to show at the same time that nothing was immediately different for Max in his perception of the world; he couldn't care less, as evinced by his fascination with the doctor's stethoscope. We also wanted to show a relationship between these two vastly different perspectives. There needed to be real interaction between Max's VI and the base style we had created for his story. Lastly, we wanted a pamphlet to provide some factual information about autism, as this was the first time that the reader encountered the term in the text. We threw all these elements together into our first version of the page.

There were so many problems. By making the parents an image within the pamphlet, the layout disconnected the reader from the parents. Max's VI didn't contribute to our

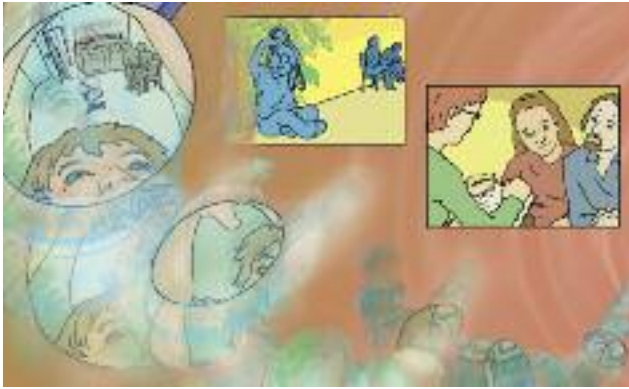
understanding of his perspective because it was developed as a visually anecdotal description of how he was different, as seen from outside his perspective. Max became the poster boy for autism, and Mom and Dad symbolic icons of parents of autism. The image was not telling their unique story. The pamphlet seems almost gratuitous. The page was a wreck.

At this point, we had to step back and reexamine the elements we needed to include in the scene: the shift in reality, Max's perspective/VI, the parents' perspectives, the parents' reactions, the doctor's perspective, and the facts in the pamphlet about autism.

After we had sorted out what the elements were, we made different choices about how to organize them within the conceptual framework. First, we let Max's VI show Max's perspective literally. The reader sees Max's reflection in the stethoscope just as Max does. The panel where the reader sees that Max is looking at his reflection in a stethoscope is from an observational perspective, like what the doctor or parents would see. When the doctor speaks to the parents, she speaks directly to them, so that it puts the reader in the parents' perspective. Rather than showing the parents' reaction by showing the parents, we let the reader experience it in their place. When they are handed the informational pamphlet, it's not done in a way that is purely informational. Instead it flips the reader's perspective on its head, in the same way that a diagnosis often overturns all our expectations about our lives.

When we began to color, we added VI by working with a glow and a vibration of the movement of the stethoscope in space. This seemed to be working well, but we quickly added too much by trying to portray the path of every swing.

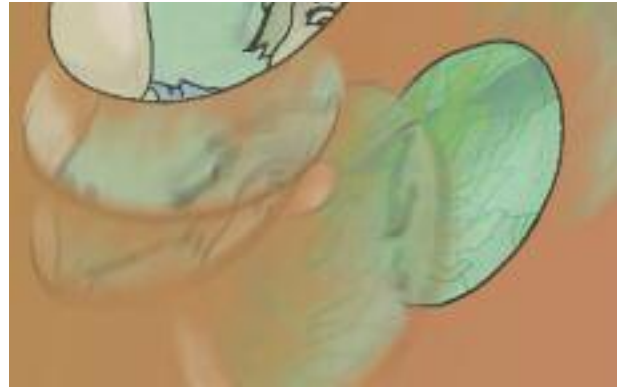
So we returned to our research, to consider what exactly the fascination was that Max found in the experience of swinging the stethoscope. We chose to focus on the combined stimulus of the movement of the circle through space and the light reflecting off of it. To create a sense of his "stimming", we first pulled back and clarified the movement. We also added echo images of the stethoscope that were offset just enough to confuse the reader's natural bifocal vision, creating a vibration in the reader's eyes as they try to reconcile two contrasting colors that are so close together that they become difficult for the brain to align. By following the single path of the swing of the stethoscope, the reader can travel with it



**Image 5: Bad Coloring**—When we began to color, we quickly added too much by trying to portray the path of every swing of the stethoscope.

across the page, without disrupting the experience of it. Lastly, we added a ripple that moves out from the vanishing point of the stethoscope's swing as a sort of metaphorical representation of the diagnosis and its effect on all the characters. The ripple continues onto the following pages.

On the next page, we drew the panels with shaky edges and erratic spacing. We began with each character in isolation as he or she reacts (or not, in Max's case) to the diagnosis. Eventually, Mom reaches across the panel to Max. Characters then begin to pair up, and by the next page we've got a community surrounding Max and taking care of each other. As things seem to return to normal, our perspective



**Image 6: Stethoscope**—We chose to focus on the combined stimulus of the movement of the circle through space and the light reflecting off of it.

shifts. Mom and Dad don't stay in the world they knew, they move instead into Max's corner of the room. The colors are overly intense and the fish eye lens perspective implies that the whole world has become dizzying.

The reader turns the page and is looking down through Dad's eyes at the pamphlets in his lap, thus beginning, with Max and his family, to take the first steps toward learning to navigate the new world of the autism spectrum.

*Jeff Benham is an award-winning freelance artist and arts instructor who works in multiple mediums. Courtney Angermeier is a teacher, comic book artist, and doctoral student. The two began work on Peoplings in a comic book class sponsored by 7000 BC, the independent comics group of New Mexico.*



**Image 7: Final Diagnosis**—By following the single path of the swing of the stethoscope, the reader can travel with it across the page, without disrupting our experience of it.



**Image 8: Second Double Page**—We began with each character in isolation as he or she reacts (or not, in Max's case) to the diagnosis.

# AGGRESSION MANAGEMENT MANGA



## AN INTERVIEW WITH RINKO ENDO

by MK Czerwiec

### *Where are you from?*

I am originally from Japan. My hometown is called Sendai, which is located in the Northeast part of Japan. That happened to be the epicenter of the earthquake we had last year. It's a big city but it's pretty laid back. Sendai is about a two and a half hour train ride from Tokyo. If you think of Tokyo as New York City, Sendai is pretty much like Chicago. I grew up there reading manga and making manga. In Japan, manga literacy is pretty high. It's not entertainment only for kids. It's the entertainment for people of all ages, all genres.

### *What brought you to Chicago?*

When I was in Junior year in my undergrad, I was going to Waseda University in Tokyo. That was the first time I came to know the existence of art therapy. One of my professors was a renowned art therapist in Japan, one of the pioneers. Attending her class and other seminars and workshops, I decided to pursue my career in this field that consists of three things I am always interested in: art, human psyche, and helping people. Back in 1997, I couldn't find a graduate art therapy program in Japan, even though you might be able to learn about it if you were in a masters program in clinical psychology or other related fields. So I came here in 2000 to do my Master's degree at the School of the Art Institute of Chicago. During that program, I did an internship at the acute care psychiatric hospital where I work now. I was hired after graduation as a mental health counselor, and then became an art therapist.

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*How did you start making manga?*

According to my mother, I have been drawing since I was about two years old. I was always interested in visual storytelling. The first book I asked my parents to buy me was called *Shoujo Manga Encyclopedia*, when I was about four. It contained all the different drawing styles, techniques, and ways to tell a story. I was probably too young for this book to utilize it or incorporate it into my artwork, but I loved my first book and always enjoyed copying pictures in it.

I first started making manga when I was about five. My first manga's story was disjointed and the graphics were disorganized. But it was an actual book that I created, drew, composed a story, printed, stapled. I still have the original copy. I was quite proud of this pretty messed-up, yet pretty cute, my very own, very first manga. In my grade school, we students were asked to submit science projects or arts and crafts at the end of the summer vacation each year. When I was in the first grade, I made this "paper theater" called *kamishibai*. *Kamishibai* may be considered one of the origins of manga, since it is a simpler form of visual storytelling. Each piece of paper (panel) has the picture (scene) on the front, and the story (text) on the back. You show the picture to your audience as you read the story to them. My *kamishibai* was about the memories of my summer vacation. I still remember how much fun I had sharing my visual stories with my classmates.

My teachers started noticing that I liked making stories, and incorporating visuals. Sometimes they asked me to make these educational manga for the class, for example, when we did multiplication tables, the concepts behind it. When we talked about the bombing in Hiroshima and Nagasaki, they asked me to make a story about it, the history. So visual storytelling was always with me. I would do my science projects as stories in manga form too. It was something I really enjoyed doing, and I seemed to be good at it.

*How did "Aggression Management Manga" come to be?*

Back in 2004, I started teaching aggression management to the employees at my hospital. We taught them about things like de-escalation techniques, how to talk to the aggressive patient, self-awareness, how to safely do physical restraints and seclusion. In 2007, I created a two-page manga for a safety issue we had. In emergency situations at work, we always assign a clear leader, someone who oversees the situation and organizes the safe steps to restrain the patient properly. But we had this problem that everyone shied away from being a leader. So I created this fictional story scenario showing what a leader should do to ensure the safety. I posted it in the bathrooms at work. I got really good feedback and response to this manga. It seemed like people really paid attention to the stories. They seemed to be able to relate to visual scenarios rather than just a list of what to do. People really responded to the text and visual combination. So I thought, "ah-ha!"

Every year we have nursing students doing psych rotations at our hospital. One of the nursing instructors at the school said that she used my two-page manga in her classes. She said she really liked it because her students seemed to respond well to it, and retain information well from visual learning tools. Along with another trainer from work, I was also co-leading aggression management workshops for graduate art therapy students at the Art Institute around that time. So I wanted to summarize what I talked about in the training. I started thinking that I should have a manga that covers all the material, so that people could read it, learn from it, and keep it, read it again whenever they needed reminders about personal safety in healthcare. So I decided to create *Aggression Management Manga* and presented it at the conference on Comics & Medicine this past summer.

*What makes manga perfect for you?*

The language barrier is a big thing for me. It's part of why I'm so enthusiastic about using manga to teach and communicate. English is my second language, Japanese is my native language. I never feel comfortable or confident enough to fully explain what I intend to say in English. People have pointed out to me that when I speak or write in English, I have a tendency to make one point from three different directions. That can be repetitive and confusing to me and to my audience. I think it's based on my fear that I will be misunderstood. I want to be understood clearly, so I say the same thing from three different directions. But in my manga, I don't feel I have to repeat myself because manga has three different languages built into it. First, you have the visual language, the art, the graphics, pictures you can see. Then second, you have text dialogue, or monologue, and sounds that we can read. Third, we have in manga a universal set of signs and signals. Say for example someone is in trouble in the



story, you see these big huge teardrop sweat signs coming out. If someone is angry, you see veins coming out of the forehead. We call this *mampu*. It's like music notes but in manga we call it *mampu*. It's sort of a universal language, but there are elements particular to manga. I don't feel I have to re-explain myself, because in my manga I have these three ways I'm communicating. I feel like I'm covered, I'm understood. When I was in Japan, when I was little, I didn't notice I used all these elements. But when I'm here, using English, I became aware that when I use manga, people pay attention to it, they get interested in it easily, they seem to remember what I want them to understand. I

prefer manga as my means of communication, because of its clarity, effectiveness, humor, playfulness, and beauty.

*What advantages and limitations do you anticipate for widespread use of manga in education?*

I feel like there is a stereotype, a stigma to manga, despite the fact that “manga” doesn't really mean a particular style or formality of drawing techniques and storytelling. The word *manga*, the direct translation, means “whimsical, random pictures that voluntarily come and go in your mind.” That's why manga has so many varieties in themes, genres, styles, and audiences. Manga can serve different purposes too—entertainment, visual teaching/learning tool, self-reflection, support, and communication. It's like a big hodgepodge of awesomeness. Manga can be about ANYTHING. And ANYBODY can make manga. That's what I like about it.

I remember that at the end of the *New York Times* article about the Comics & Medicine conference, the reporter said that the conference combined serious medical issues with the lightheartedness of comics. That's something that I am truly passionate about doing: talking about serious stuff in a funny and hopefully beautiful manner, through utilizing the graphic power of comics and manga. That's an advantage that comics, and manga, can bring. My intention is not to minimize the subject, and certainly not to mock it. I'm talking about serious topics—aggressive patients, mental health, and psychiatric care. But humor brings something human, warmth, to topics perhaps people don't want to talk about, or touch, or they have anxieties about. I talk so much about self-awareness in my

*Aggression Management Manga*. Dealing with aggressive patients brings up the caregivers' own issues, their own culture, their own history of violence, whatever that may be. This is ultimately unavoidable, but people want to avoid recognizing their own issues at play when caring for their patients. In my manga, I used myself as an example and shared my own experiences of being physically assaulted. I did that so that people could relate to my stories, and they could feel that they are not alone; they are not the only ones who are scared. I am sometimes scared too, but I try to learn how to manage my fear to provide a better care to my patients. “How can we, healthcare professionals, manage our own issues and emotions? How can we use our insight to provide the quality care?” Through my manga, I wanted to ask myself these important questions, and hopefully inspire others to start searching for their own answers.

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I realize that there are some generation gaps in manga literacy. For example, my parents sometimes say they get easily tired and even frustrated reading manga. Maybe they feel bombarded by visual stimulations and information overload that they are not used to experiencing. I understand that. Also, some people feel comics and manga can't be taken seriously. They may say it is too childlike,

too comical. Some people may love comics and manga, while others would never flip through pages, or even lose interest in certain topics BECAUSE they are explained in comics and manga. My way of storytelling is funny, but I have to be aware that some people may take it as disrespectful or even offensive. They may even think that I'm making fun of certain situations or people's vulnerability. Lightheartedness is a great thing, but I have to use it with caution and handle it with care in my graphic stories. I also have to think about the issue of confidentiality. I often use my pet cat and myself as characters to maintain patients' confidentiality. I also think animals' cuteness and silliness can minimize and lessen the intensity of the stories and graphics. But some people may question or misunderstand my creative intentions. It is my responsibility as an artist to be aware of both advantages and disadvantages of utilizing graphics in my storytelling, communication, and teaching.



*You highlight the importance of culture in your manga. Tell me more about that.*

Culture can mean a lot of different things. It doesn't always mean you are from a different country, or speak a different language. How you grew up at home, what your communication style is like, if you avoid conflict or not, your gender-associated behaviors, how you've been taught to protect your safety, all those things can be your "culture." They all play a part in how you handle threats to your safety today, so I talk about those things in my manga.

*What are your hopes for Aggression Management Manga?*

It is my hope that I can find as many avenues as possible to distribute it to other healthcare professionals and future clinicians. I'd love to hear their feedback. When I made this manga, I didn't see it as entirely medical or fully educational, but as "reminders" they can keep, and read whenever they need to remember the importance of safety and self-awareness. It's reminder manga. I would love to do some collaboration manga, working with helping professionals of all different disciplines—such as nurses, teachers, doctors, and social workers.

Throughout my life, manga has taught me so many important things. It has guided me to amazing experiences and people. As I continue to create my manga, I hope my creations can do the same magic to some people—planting a tiny little "seed" of insight, and encouraging people to nurture that seed.

*rinkoendo@gmail.com, comicnurse@mac.com*



# Monsters and the Ghosts of PubMed

Alice Dreger

Sarah McCord can't quite remember when she discovered that PubMed was still calling conjoined twins "monsters." She does, however, remember being startled.

"It bothered me," she wrote to me, "because it seemed like there were all kinds of news stories about conjoined twins being surgically separated, and I knew that there would be more searching on the topic than there had been in the past. I wondered how seeing this term might affect a family member looking for information."

Sarah is Head of Reference & Instructional Services and Associate Professor of Library Resources at the Massachusetts College of Pharmacy and Health Sciences. As a medical librarian, she thinks not just about what healthcare professionals need to find, but also what patients and their families will encounter.

Sarah and I found ourselves in conversation after she wrote to advise me of something she had done, something that startled me far more than the subject term "Monster" had startled her: Sarah was writing to say that, since 2007, she had been steadily nudging the National Library of Medicine (NLM) to stop listing human offspring as monsters, and that she had recently succeeded. The NLM had officially replaced "Monsters" with "Abnormalities, Severe Teratoid" in the official Medical Subject Headings (MeSH) used in PubMed. And Sarah wasn't done; she was pushing for the for-profit medical databases, including Elsevier's EMBASE, to do the same, and she was succeeding.

My mouth dropped open when I read her first email describing her efforts. And I thought immediately of three people.

The first was a man named Tom, born with hypospadias (an anomaly of the penis), who appeared in the 1996 homemade activist film, *Hermaphrodites Speak!* In the film, Tom remembers that, in spite of surgeons subjecting his genitals to "normalizing" surgeries, no one told him the name of his condition. One day, someone inadvertently dropped the word "hypospadias" in reference to him. Young Tom snuck off and looked up "hypospadias" in the encyclopedia, only to find this: "*Hypospadias*; see *Monster*."

The second was Deb Costandine, whom I helped figure out what her still-born conjoined twins had looked like thirty years earlier.<sup>1</sup> When I had sent Deb a copy of a case report from a 1980 issue of *Archives of Gynecology* of conjoined twins who resembled her lost sons, I had had to write, "I have to warn you that it includes the obnoxious term 'monster' and explain that this was used by physicians until the 1990s as a standard term for a major birth defect. Some still use it, but it is obnoxious because of what it connotes. [...] It is obvious that people are not monsters, and doctors should have stopped using that term a long time ago."

And the third was George Annas, whose 1987 article in *The Hastings Center Report* had articulated for me something I had been struggling to explain in my own work on conjoined twins.<sup>2</sup> Annas disdainfully called the business of subjecting conjoined twins to a separate (indeed, lethal) kind of medical ethics "monster ethics"—an ethics that says surgeons can do whatever they want up until the point when they make these "monsters" human, even "kill one to save the other."

When Sarah first got in touch, she explained she was letting me know about the PubMed shift for several reasons: "(1) these changes may affect the way you search for information, and (2) these changes will affect the way (a very small part of) your work is classified and categorized. And, honestly, reason (3) for dropping you this note is that I was delighted to discover a scholar who might actually care that these changes [...] have been/will be made."

Care, I did. I immediately wrote Sarah back fan mail, telling her there was no doubt in my mind her action would benefit real people, people like Tom and Deb. That graphic horror movie label would no longer be slapped on the marquee of their lives, at least not in PubMed.

Sarah admitted, "I did have a colleague ask if making the changes would be a lot of work 'for such a small number of articles.'" (A case of monster librarianship? Why worry about what happens to those labeled "monsters?") She said she responded by reminding her colleague about how ADA-required curb

cuts have turned out to help far more people than just chair-users. "Big changes come from small changes," she concluded.

Of course, it seems unlikely that any of the sensible folks at the NLM found her suggestion anything but long overdue. Sarah hastened to point out to me that it was the NLM staff, not she, who came up with the new term. Still, it says something that it took until 2010 for the largest public database of medical literature to shoo out this particular ghost of medical history.

By coincidence, monster ethics came up this past weekend in an email correspondence with my good friend Kiira Triea. When Kiira's mother had been pregnant with her, doctors gave her mother progesterin to try to prevent a miscarriage. Consequently, Kiira, a genetic female, was born with virilized genitalia. As a terribly femme teenage boy, Kiira ended up in the infamous Johns Hopkins clinic of John Money. Money tried to make the boy more manly—Kiira was messing with Money's theory that gender comes from nurture—but failing that, Money finally "let" Kiira become a girl.<sup>3</sup>

Lately I've been pushing Kiira to do more autobiographical writing. In her last email, Kiira was sharing my frustration with a disciple of Money who keeps getting away with sub-human treatment of sex-atypical children. "They just tell a few monster stories, so the parents will come around to the intervention the clinician wants to do," she wrote to me about this kind of clinician, "and everyone understands how important their 'work' is."

"Oh," she added, "there's the name of my book: *Monster Story*."

Like me—like Sarah—Kiira knows that only medicine has enough mojo to make a baby a monster. Or to make her a person, with just a charmed word.

Alice Dreger is Professor of Medical Humanities and Bioethics at Northwestern University. [a-dreger@northwestern.edu](mailto:a-dreger@northwestern.edu)

- 1 Dreger AD. Products of Conception. In: Bioethics Forum: The Hastings Center; 2007.
- 2 Annas GJ. Siamese twins: killing one to save the other. *Hastings Cent Rep* 1987;17:27-9.
- 3 Triea K. Power, Orgasm, and the Psychohormonal Research Unit. In: Dreger AD, ed. *Intersex in the Age of Ethics*. Hagerstown, Maryland: University Publishing Group; 1999:141-4.

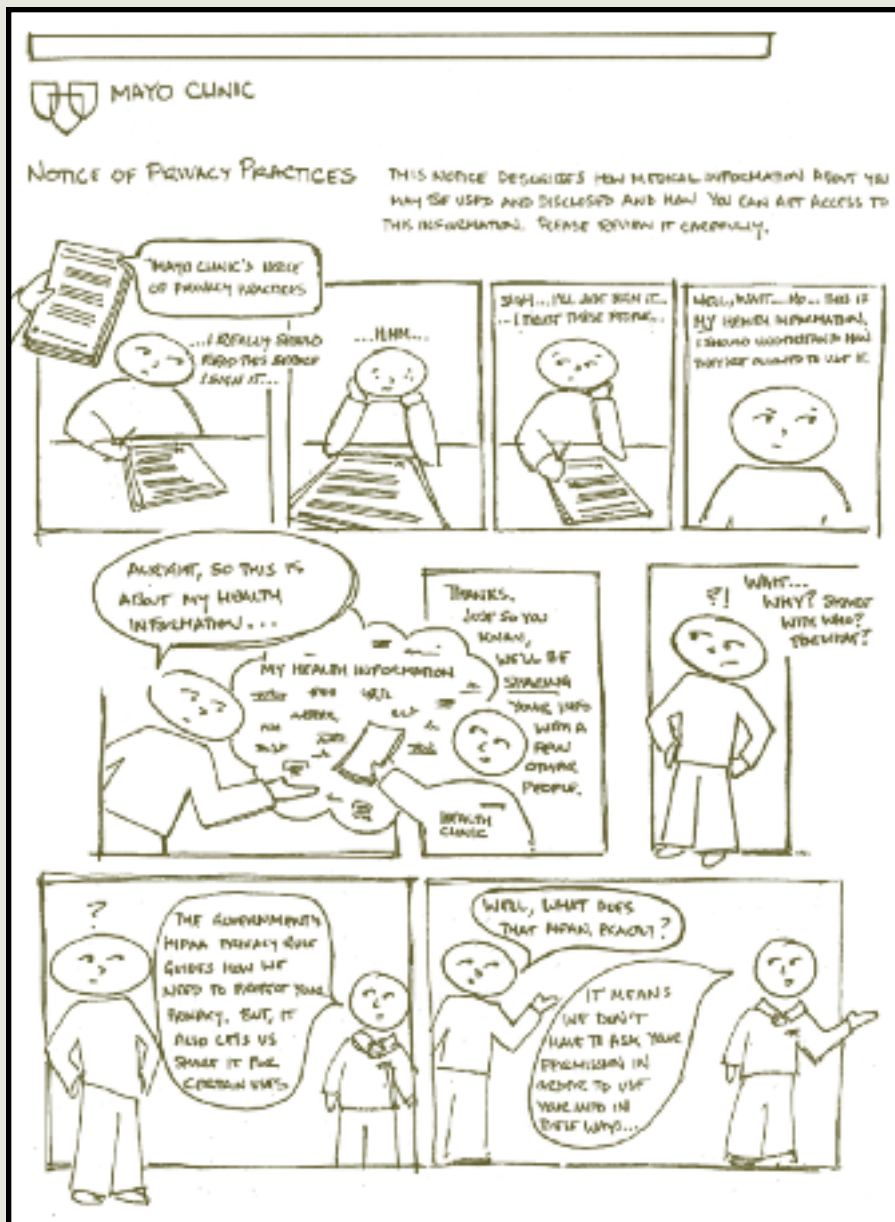


# Picture This: Illustrating the Future of HIPAA Documents

Leah Eisenberg and Rose Anderson

A single visit to a new health care provider can leave patients with a pile of paperwork. There are consent forms, appointment reminders, prescriptions, and various other instructions that they are expected to review and comprehend in short order. In that pile, one of the documents that is most tempting to skim rather than read is the “Notice of Privacy Practices,” due to its length, complexity, and the fact that patients only have to acknowledge receipt of the form, rather than agreement with it.

The Notice of Privacy Practices is a portion of the information governed by the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule. HIPAA was enacted by the United States Congress in 1996, in part to establish a framework for protecting the privacy, security, and availability of patient medical information. The Rule requires covered entities to give patients notice of their institutional privacy practices. This notice must explain how the entity can use and disclose the individual’s protected health information, and the patient’s rights in relation to those uses.<sup>1</sup> The Rule divides uses and disclosures of personal health information into two general categories: those that require patient authorization and those that do not (there are also a few special circumstances where patient consent is not required, but objections are honored). Covered entities must obtain written consent from patients in

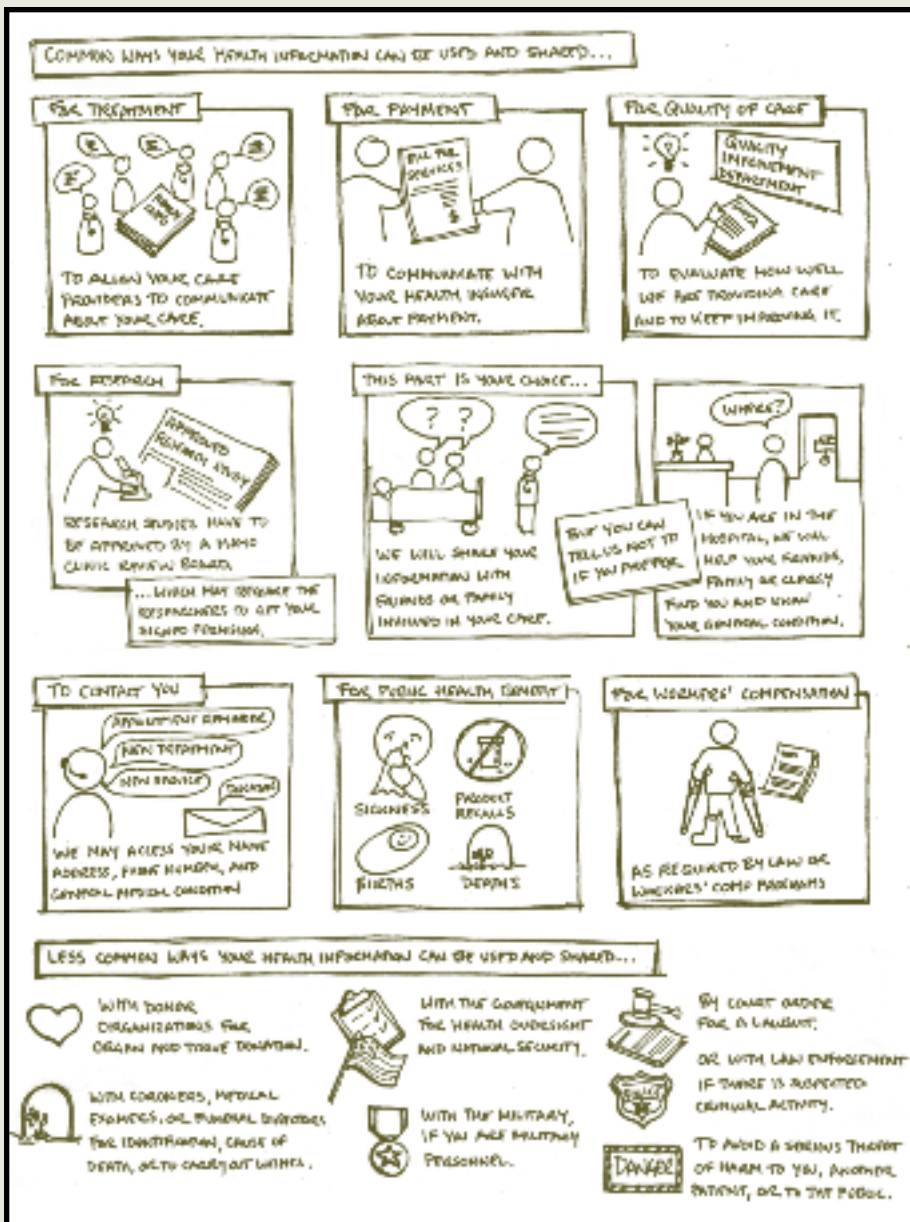


order to use patient information requiring authorization, but only need to provide documentation containing “sufficient detail to place the individual on notice of the uses and disclosures that are permitted or required” for the rest.<sup>2</sup>

Preliminary studies suggest that patients are not coming away from HIPAA forms with a clear understanding of what uses and disclosures it covers.<sup>3,4</sup> This violates the spirit, if not the letter, of the law. If notice is important, then it stands to reason that comprehension is as well; otherwise, the HIPAA notices given to patients are mere formalities. What can be done to improve patient understanding of HIPAA documents? Using plain language is crucial, but the information remains challenging to comprehend even when written at an

eighth-grade level, since it contains many discrete details that do not follow a narrative flow. Moreover, the information itself is dry; it is questionable whether patients would be interested in reading it even if it were presented in completely clear prose. A new approach is required. In recent years, there has been a rise in the use of stylized, comic-style illustrations for patient education purposes.<sup>5,6,7</sup> Graphic documents convey complex information in an engaging, accessible format. Could a similar approach aid patient understanding of required HIPAA documentation?

Two illustrated HIPAA documents have been developed at our institution; the required Notice of Privacy Practices, and an authorization to use and disclose personal health information for



rather than spend the time deciphering it. A helpful representative of the health clinic shows up and informs him that his health information might be shared with a few other people as well. Rather than use language that downplays concerns that a reader might have about this statement, the illustrated form takes full advantage of these, showing the main character unhappily concerned about what this could mean in order to hook readers in and make them want to learn more.

While the Notice of Privacy Practices form begins and ends with a conversational style, it switches to a more didactic tone in the information-heavy middle sections of the notice. This enables a large amount of information to be conveyed in a concise way. Creating a narrative series for each potential use of protected health information could have resulted in a book-length work, which, while interesting, would not be something that could be reviewed prior to a doctor's office visit. The illustrated elements are used to organize the information, indicate levels of information, and to provide vignettes to further clarify what the statements mean. There is a hierarchy both to the page itself and within each frame. The title of each frame provides a headline for the intended use of the information—e.g. “for quality of care”—while the copy and pictures within the frame provide more detail about that usage. The illustrations also suggest example scenarios for the reader. The “if you are in the hospital” illustration brings to mind a scene where a concerned family member is looking for his or her loved one. Patients can easily relate to the need for such a disclosure, in contrast to the confusing terminology used to convey the same information on the traditional form which refers to sharing information for “Facility Directory/Patient Census.”

The choices about the style of drawings used on the illustrated forms were made as deliberately as those pertaining to the content and layout of the document. These example forms use a very simplistic, cartoonish style with minimal detail. Despite the straightforward line style, different combinations of eye, eyebrow, and mouth shapes can still be used to convey emotions like thoughtfulness, confusion, and satisfaction. The simplicity of the illustrations

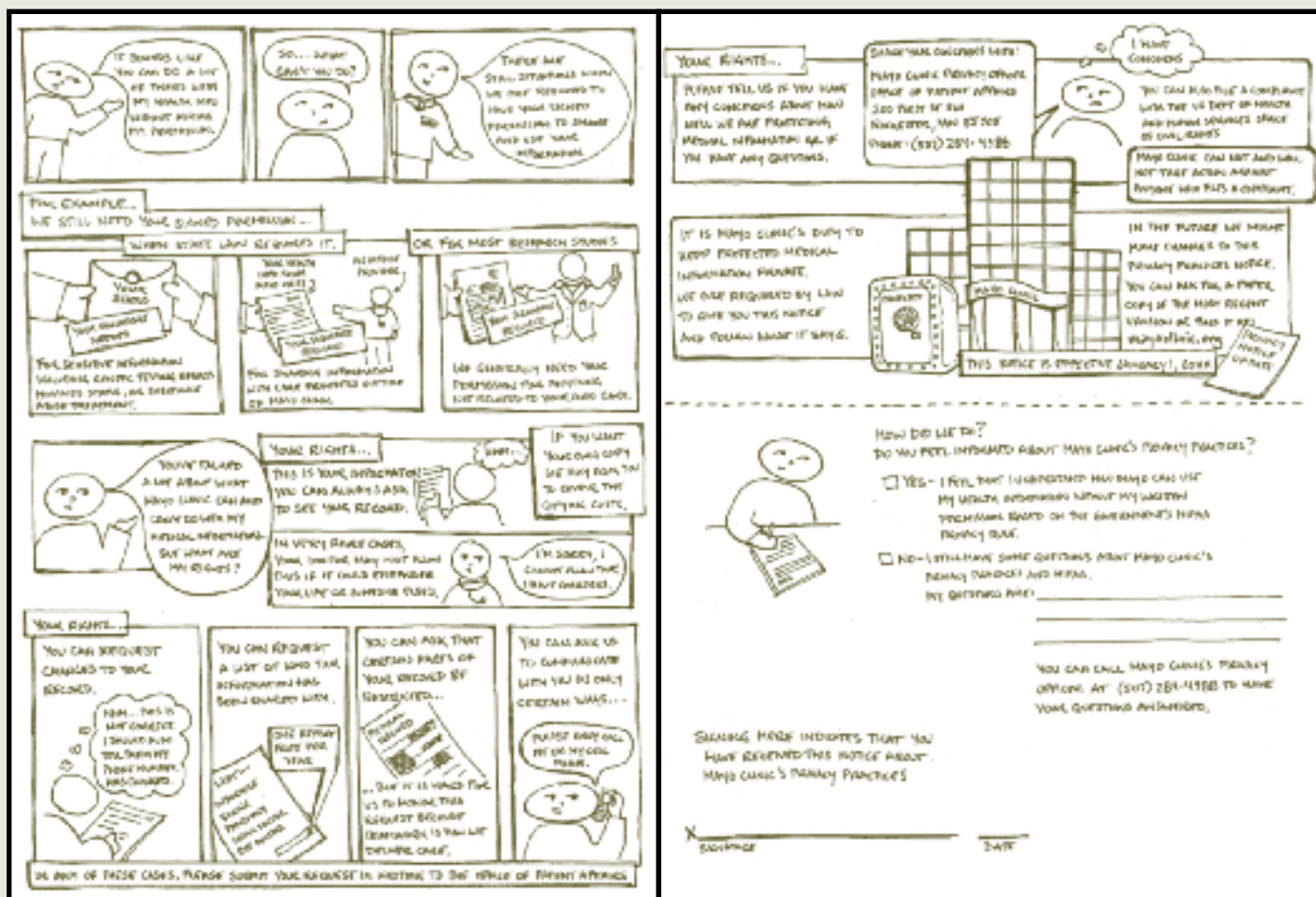
research purposes. They are based on the Institutional Review Board (IRB)-approved written documents currently in use at Mayo Clinic, but contain far less text. Our commitment to producing an illustrated form meant that it was necessary to control the amount of text we included, lest the new form become nothing more than a typical written form accompanied by illustrations. It is important to emphasize that while text was omitted, pertinent information was not. Where traditional HIPAA forms would have included extensive lists of possible disclosures, we distilled the information into short written explanations that could be further “explained” through accompanying illustrations. For example, the Mayo Clinic Notice of Privacy Practices contains an eighty-word

statement detailing the possible use of patient information to contact individuals in order to request philanthropic contributions to the institution. The graphic form conveys this idea with a drawing of an envelope and the word “donation.” The same information is conveyed, but in a much more concise manner.

The illustrated Notice of Privacy Practices form starts from the point of view of an imagined recipient. This character's questions and concerns are used as a device to gain readers' interest and emphasize why they should care to understand the information at all. It shows the imagined recipient of the form sighing in resignation as he attempts to understand the form and empathizes with his temptation to simply sign it



**Picture This:**  
Illustrating the Future of HIPAA Documents (continued from previous page)



works to balance the visual denseness of the text. Hand-written text, rather than a standard type font, was also a purposeful choice for this example, meant to avoid a dissonance between the organic style of the drawing and the potential rigidity of a traditional font.

The illustrated HIPAA documents contain general rather than state-specific information, and are intended to serve as prototypes of what graphic HIPAA forms could look like. The presence of this tangible example advances the concept of nontraditional HIPAA documents in more meaningful ways than an abstract discussion could. It not only gives those who could not imagine an illustrated form a chance to see a concrete example, but it also shows that conveying complicated information in a non-traditional format is indeed possible.

Our goal in developing illustrated HIPAA forms was to create something that is not only understandable, but also interesting to read. Infusing the

dull information on these documents with interesting, yet concise, narrative details proved challenging, but doable. The illustrated forms displayed here are just one example of how this challenge can be approached. At this point, it is too early in the process to conduct quantitative evaluations of the graphic format. It is important to give a novel approach like this a chance for further development. A common response to something unfamiliar is often disapproval, regardless of its potential. Allowing critics a chance to become accustomed to the novel format before inviting feedback will increase the likelihood that they will fairly judge the concept for its potential to improve patient interest and understanding. The forms were not developed to show the sole way that illustrations can be used in conveying HIPAA information, but rather to begin a conversation at Mayo Clinic about the use of illustrations on medical and legal documents.

*Leah Eisenberg has a MA in Bioethics and a JD, and has written several patient consent forms used for research biobanking at Mayo Clinic in Rochester, MN.*

*Rose Anderson is a senior designer at the Mayo Clinic Center for Innovation where she leads research, design and development efforts to transform the delivery and experience of health care.*

- 1 45 CFR §164.520(b)(ii) (2010).
- 2 §164.520(b)(ii).
- 3 Collins N, Novotny N, Light A. A cross-section of readability of Health Information Portability and Accountability Act authorizations required with health care research. *J Allied Health*. 2006 Winter; 35(4):223-5.
- 4 Paasche-Orlow M, Jacob D, Powell J. Notices of Privacy Practices: a survey of the Health Insurance Portability and Accountability Act of 1996 documents presented to patients at US hospitals. *Med Care*. 2005 Jun;43(6):558-64.
- 5 Gillies P, Stork A, Bretman M. Streetwise UK: a controlled trial of an AIDS education comic. *Health Education Research*. 1990;5(1):27-33.
- 6 Green MJ, Myers KR. Graphic medicine: use of comics in medical education and patient care. *BMJ*. 2010;340:c863.
- 7 Comic Books Featuring 'Super Heroes' Educate Young Men About Testicular Cancer. 2010 [updated 2010 cited 2011]; Available from: <http://www.medicalnewstoday.com/releases/202287.php>.



# SAVING GRACE:

## Teaching about Breast Cancer Diagnosis and Treatment Using Comic Form

Veta Salubi

I worked as a product specialist for a world-renowned manufacturer of diagnostic equipment in Nigeria for seven years. During that time, my job was to convince and teach doctors, politicians, and decision makers in private and public practice of the need for high-end medical technology such as computed tomography scanners, MRIs, mammography and digital X-ray equipment. It may seem strange for readers who live in developed countries that there would be much convincing to be done for essential equipment like this, but here in my country it was and still is a hard sell indeed. Many times I was totally frustrated, but the idealistic goal of saving lives pushed me to go on.

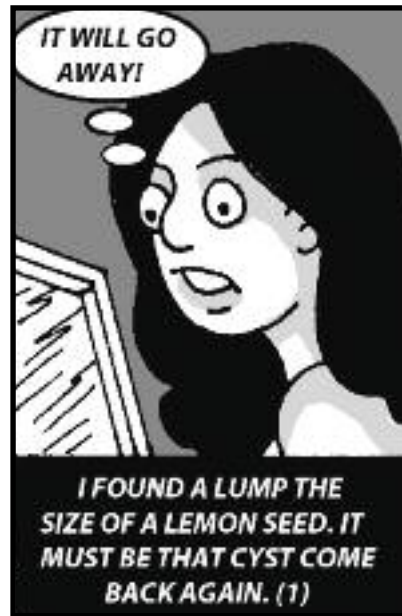
The key challenge with each stakeholder—the doctor, the decision maker and the patient—was (and still is) a lack of information. People do not know what is possible or what they stand to benefit from early detection or outright prevention of disease with the use of medical technology. Add to that the stigma of diseases such as cancer, which is a growing epidemic but still considered by many in the populace to be the result of evil machinations and feral practices. Then there is the increasing complexity of hospital practice across internal and external referral networks for secondary and tertiary care. Many of these challenges are the offshoot of attempts to resolve the ethical dilemma here for most doctors seeking to balance capital investments in high-end equipment with answering questions of ownership from the State, peers, and patients, yet still maintain some kind of control by giving as little information as possible about what they actually do rather than advertising their services. All these issues form a veritable mental block in the minds of patients and, believe it or not, in the minds of many doctors when it comes to making positive decisions regarding disease management in general.

In Nigeria, the usual response of a prospective cancer patient is one of fearful denial and a forceful belief in divine intervention to make a health crisis go away. The disease is viewed as a manifestation of the devil and the traditional response in such situations is to believe, and to cast the devil out to restore health. As a health professional peddling diagnostic solutions for a growing epidemic of non-communicable diseases to doctors and decision makers, I needed a strategy to reach the willfully ignorant to save the lives of those experiencing illness. I feel strongly that if people know their options then perhaps they will demand their right to international standards of care. I thought to myself, “What medium could I use to teach and to show without alarming or insulting? How could I build confidence while simplifying the complex network of decision making in disease management?” Every disease case has its nuances and any presentation I might make must show the path of least resistance towards resolving the

clinical case while maintaining the emotional integrity of the patient and the reader. The patient must learn just enough to ask the right questions.

Comics, as a graphic medium of expression, are the ideal choice for communicating urgent information in a controlled sequence that guarantees understanding in the shortest time. The very sequential nature of this medium is perfect for describing ‘workflow,’ which I define as the path of least resistance in a multifaceted process. In our comic book story, *Saving Grace*, we are able to use excerpts from the journal of a cancer patient to show timelines, doctors’ notes for clinical detail, and a Note to Self format to define technologies, clarify processes, present options and build urgency. A summary page showing a ‘workflow map’ at the end of the comic provides a big picture of the entire case management process.

*Saving Grace* is a very simple and not too optimistic story that follows through the process of initial diagnosis to post-treatment follow up while giving the reader a direct emotional contact with the protagonist. Grace is a 40-year-old mother of one who has breast cancer. Her story is told as excerpts from her journal expressing her hopes and fears and also providing words of advice and caution (that she writes in notes to herself) that draw the reader into her experience as she learns how to treat the disease. Before writing this story, I had never personally known anyone who has



or had breast cancer. I heard second hand stories, listened to reports from doctors, heard the rhetoric from NGOs, and read about increasing statistics. I think I chose this subject material because I am a woman who just happens to have the predisposing factors for breast cancer—above thirty, never given birth and early menarche. Also, at the time this project came up, I had just put on weight suddenly and noticed my right breast had become much larger than the left and it ached. In short, I was afraid. I was so afraid I did not want to do anything about it. Like Grace in the story, I hoped it would just go away.

(continued on next page)

## SAVING GRACE:

Teaching about Breast Cancer Diagnosis and Treatment Using Comic Form (continued from previous page)

In my research for the book, I found a woman willing to speak to me about her experiences with breast cancer. She seemed ready to share her story, and perhaps also leave a part of herself behind through this project. At the time we spoke, she was about to finish radiotherapy. She was still afraid and unsure what her disease outcome would be. Nevertheless, she was the most positive person I have met and I tried my best to let her strangely reassuring mix of positivity and fear be present in my character Grace. This mix of positivity and fear makes her real, and makes Grace's story real as well. The book is just 16 pages but it overflows with angst and information that every woman, and to an extent every doctor, should know about handling breast cancer and managing the patient with breast cancer.

Many of the texts I researched as references for *Saving Grace* fell short in two ways. They were too long to read, and too much information made them difficult to follow.

Treating breast cancer is not an exact science, hence treatment plans A, B and so forth, depend on the type of cancer and how the cancer responds to treatment. For my purposes, the key elements of treatment are diagnosis (the formulation of a treatment plan) and follow up. In *Saving Grace*, after Grace recovers from the alarm of confirming she has breast cancer, she proceeds to find out as much as possible about the disease. This is not depicted in the art but in the notes and definitions alongside. There are 3 stages of diagnosis made before Grace is actually confirmed to have breast cancer. For further emphasis on conclusive detection, *Saving Grace* has an entire page of describing nine other possibilities that her symptoms could have been beside breast cancer. The point here is: Evidence from the leading teaching hospital in the country says that only one in ten women with breast symptoms actually presents with breast cancer and we tried to make this clear here in the waiting room scene.



When Grace learns she has breast cancer, we feel her panic and confusion but we also understand the urgency requiring her to seek immediate treatment passed across to the reader. The Note to Self mechanism indicated by the numbers in brackets after her journal entries are expounded on to emphasize and reemphasize salient issues like immediate detection, family support, reinforcing statistics for survival rates with early detection, clearer definitions of clinical terms. In short, we try to list everything a woman would naturally require more information about so she assumes control of her health situation. It even includes managing breast cancer during pregnancy. Yes, Grace gets pregnant in our story. In writing this into the story, we felt having a new life growing inside Grace would give our women readers a sense of the hope that many women leaving with breast cancer have and the joys they live for despite the disease.

I've skipped some scenes to get to the baby part so let's back track a little to meet the doctor that saved Grace. According to Grace, Dr Badmus is a good doctor but not because he cured her. In fact there is a scene where one patient goes away not at all happy. No, Dr Badmus is not a miracle worker, but Grace trusts him because she can talk to him. Doctor-Patient communications has become a serious subject in medical education because we believe two-thirds of



I think *Saving Grace* is a good story and that it meets the objective for which it was written and drawn: to communicate a challenging subject gently if not too subtly to the patient, friends and families of patients, the average woman. It even has one or two things to teach the doctor about managing the patient as he or she manages the disease. We have not written much about workflow analysis or workflow management and we have deliberately avoided the mention of too technical terms (every thing else, we define and explain) but we have implied it in the presentation of the subject. I think graphics serve the purpose of the implication of words not spoken but seen and lessons not learned but absorbed. This is what makes comics a most interesting and successful medium and what makes *Saving Grace* a story for every woman, and every man who loves them.

the healing process is empathy, earning trust. A patient needs to trust that doctors will do their best for him or her. Doctors need to note that their personality and communication style play a major role in

effectively treating a patient. It is essential for doctors to compose themselves to elicit trust from frightened and sick patients. That is a note to doctors.

*Saving Grace* presents many clinical details from the doctor's perspective (panels on doctors' notes and treatment) which have been simplified graphically and with a little playfulness. When Grace begins to receive radiotherapy, she observes that the targeting lasers on the radiotherapy equipment reminded her of the shooting games her son loved to play and that she shared this idea with her son. Children find it difficult to understand the management of disease, but they feel every ounce of the fear the adults around them feel. Helping them to come out of themselves using a gimmick as simple as this can be a blessing for the child and the suffering parent.

Another type of gimmick, which many may not agree with, is the award giving to survivors who cross set milestones post treatment. It may seem kind of corny but the objective here is to let the reader know that life must be celebrated and the only way to celebrate life is to live—to reach and celebrate treatment milestones and whether you have breast cancer or not. Note to Self.





# DOWN THERE

Sarah Rodriguez

What does the use of a euphemism reveal?

In a *Journal of Sexual Medicine* article published late last year, a dozen physicians published evidence, based on the responses to a retrospective questionnaire by 258 women, of the sexual benefits of what they call female genital cosmetic surgeries. These surgeries include removing the clitoral hood, reducing the labia, and tightening the vagina. Physicians perform these surgeries, and women seek them out, for aesthetic reasons—to ‘correct,’ for example, ‘unattractive’ labia—as well as for their supposed capacity to increase sexual enjoyment. The survey’s first question, regarding the woman’s “initial reasons for surgery,” offered as its first option “to look better down there”—the euphemism is meant to encompass a woman’s external genitals and her vagina.<sup>1</sup>

Now, I have spent a lot of time—a lot of time—thinking about the external female genitals, in particular the clitoris, having written my dissertation (which I am now revising into a book) on the therapeutic use of female circumcision and clitoridectomy in the United States since the late nineteenth century. And there are many things that bother me, both about this survey, and about the surgeries which it surveyed. But what I am going to focus on here is the authors’ use in their survey of the euphemism ‘down there’ to describe the external female genitals which they had surgically modified.

Gynecologist Michael P. Goodman and his fellow authors conducted their survey in response to an American College of Obstetricians and Gynecologists opinion issued four years ago, which warned that the promotion of female genital cosmetic surgeries as sexually enhancing was not based on empirical evidence, nor were the surgeries considered clinically routine or medically indicated. This, according to ACOG, made such surgeries “untenable.”<sup>2</sup> The survey, then, was meant to provide evidence supporting the surgeries’ safety and efficacy in enhancing sexual experience: the nine questions asked the female respondents if they considered that they had had any complications post-surgery, as well as whether they were satisfied it had made sex better for them, and if they had perceived an increase in the satisfaction of their (assumed male) partners following the surgery. In the article describing their results, the authors go out of their way to note the existence of a “wide range of normality” among women, ‘down there,’ but in fact they present a very narrow range of what ‘normal’ female genitals look like, and implicitly suggest that the normality of female genitals includes a sexual function defined not solely (or even perhaps primarily) by the possessor of the genitals, but by her (assumed male) partner.

Granted, the survey was about surgeries to reduce ‘large’ labia, modify the vaginal opening, tighten the inner vagina, or remove the hood of the clitoris—all surgeries in the genital area, so

perhaps the use of a blanket term is justified. But the use (and presumed usefulness for the survey respondents) of a euphemism instead of the more anatomically related terms a gynecologist may use, say, “to look better in my genital area” or even “make my vulval area more appealing,” is disrespectful to both the female body in general and in particular to those female bodies upon which they operated.

But their use of the euphemism does, I think, graphically illustrate their opinions about these parts of the female body, opinions which are in stark contrast to those of earlier twentieth-century physicians like gynecologist Robert L. Dickinson, who documented his appreciation for the variety of shapes, sizes, and colorations of women’s multi-part external genitalia in his 1949 book, *Human Sex Anatomy: A Topographical Hand Atlas*. Dickinson, it should be noted, was very concerned that his patients have an enjoyable sexual life, which he regarded as fundamental to a happy marriage (as well as one of its benefits). Rather than surgically altering the labia or the clitoris—organs he respected for their diversity—he suggested different sexual techniques and positions to better enable both women and men to enjoy sex by concentrating on ways that the sensitive genitals of both could be stimulated. Michael P. Goodman and company would do well to look back at this predecessor in gynecology, one who believed that naming the female genitals was a central component of understanding them.

*Sarah Rodriguez is a research assistant professor in the Medical Humanities & Bioethics Program and is interested in the history of women’s sexual and reproductive health in the United States.*  
srodriguez@northwestern.edu

<sup>1</sup> Michael P. Goodman, Otto J. Placik, Royal H. Benson, John R. Miklos, Robert D. Moore, Robert A. Jason, et al, “A Large Multicenter Outcome Study of Female Genital Plastic Surgery,” *Journal of Sexual Medicine* (2010) 7: 1565-1577; ACOG Committee Opinion, “Vaginal ‘Rejuvenation’ and Cosmetic Vaginal Procedures,” *Obstetrics and Gynecology* (2007) 110: 737.

<sup>2</sup> ACOG Committee Opinion, “Vaginal ‘Rejuvenation’ and Cosmetic Vaginal Procedures,” *Obstetrics and Gynecology* (2007) 110: 737.

# Impressions of Female Genital Cutting

Carrie Channell

In my (admittedly non-exhaustive) thesis research on the debate over female genital cutting (FGC) I encountered some interesting depictions of the practice, both textual and pictorial. All of the representations I'm discussing here originate from Western academic literature, including descriptions of how the practice is graphically depicted in Africa. There appears to be a wide range of variation in these descriptions and images, possibly suggesting some inconsistency in perception of FGC.

Written descriptions targeted at Western audiences are often shockingly graphic—and by “graphic” here I mean thorough and very detailed. Authors frequently describe FGC as torture or child/wife abuse. On their website, the World Health Organization (WHO) vividly describes the various forms of the practice from least to most invasive, routinely emphasizing the most dangerous potential side effects, often leaving the reader with the impression that all degrees of invasiveness are exceptionally harmful. The WHO defines FGC as “all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons.”<sup>1</sup> The organization further characterizes the practice as “harmful to girls and women in many ways,” including that “it is painful and traumatic,” and “causes several immediate and long-term health consequences.” However, I did not encounter vivid pictorial presentations of circumcised genitals or pictures of genitals exhibiting the “long-term health consequences” in the WHO or the peer-reviewed materials on FGC. Most of the papers I read included graphs to chart regional prevalence or type of procedure, but actual pictures of circumcised genitalia were relatively rare, and most of those consisted of line drawings showing types of FGC and some of the surgical techniques employed. The intensity of the language stood in stark contrast to the sterility of the pictures.

Some other images I encountered were the human faces of FGC: sad-faced mothers holding teary-eyed daughters. The last two official WHO statements calling for eradication of FGC featured a semi-abstract sketch of a woman's face, her head covered with a scarf, a single tear rolling down her cheek. The implication is obviously that the practice offers nothing but pain and suffering. It also implies that women are forced to undergo the procedure against their wills. In fact, a number of African women testified that, although the act itself was painful, the celebrations around it were joyous occasions.<sup>2</sup>

As far as I could tell, African women were not a target audience for graphic depictions of FGC. Although not specifically stated, this is likely because practicing women know what circumcised genitals look like. However, I did find one other target audience: African male members of FGC-practicing tribes. In the Sudan, for instance, activists conducted education campaigns wherein they show men models of “normal” female genitalia and then show the men extremely graphic and bloody videos of the circumcision surgery. The videos included shots of little girls crying. Many of the men who attended these sessions indicated shock and disgust at what their wives and daughters had undergone; but it took the visuals to move them from “this is women's business, it is not for us to know,” to wanting to alter or end the practice.<sup>3</sup>

I find it interesting that the different forms of graphic depiction seem to reflect the different ways in which the practice is viewed. Although many activists seem to assume that, given a certain amount of education and knowledge, all people will come to the same conclusion regarding FGC (i.e., total eradication), in fact, there are a number of different opinions on the best options both within and between cultures. Perhaps just picturing the practice may in some cases be muddling the conversation.

*Carrie Channell recently graduated with her MA from the Medical Humanities & Bioethics Program. cbchannell@yahoo.com*

<sup>1</sup> World Health Organization. 2008. Female genital mutilation. Electronic document, [http://whqlibdoc.who.int/publications/2008/9789241596442\\_eng.pdf](http://whqlibdoc.who.int/publications/2008/9789241596442_eng.pdf), accessed March 23, 2009.

<sup>2</sup> For example, see Fatima's testimony in Assaad, Marie Bassili. 1980. Female circumcision in Egypt: social implications, current research, and prospects for change. *Studies in Family Planning* 11(1):3-16.

<sup>3</sup> Gruenbaum, Ellen. 1982. The movement against clitoridectomy and infibulations in Sudan: public health policy and the women's movement. *Medical Anthropology Newsletter* 13(2):4-12.



A DOCTOR SPEAKS ...

IT HAPPENS QUITE OFTEN AND PROVIDES US PROFESSIONALS WITH AN INTERESTING DILEMMA

HAVE YOU EVER HAD A PATIENT WHO...

COCK

CASUALLY LAUNCHED INTO OBSCENE VERNACULAR DURING A CONSULTATION?

OR HAVE YOU HAD SOMEONE USE BASE LANGUAGE TO DESCRIBE BODILY FUNCTIONS OR, ER, 'LEISURE ACTIVITIES'?

WHAT WAS THE CONTEXT?

HOW DID YOU REACT?

WHAT WE ARE TALKING ABOUT IS

AND WHAT DID THAT REACTION SAY ABOUT YOU?

SHIT

DR IAN WILLIAMS

# GRAPHIC LANGUAGE!

AND THIS WILL BE A GRAPHIC DISCUSSION

(THE EDITORS HAVE ASSURED ME THAT PROFANITY IS ACCEPTABLE SO LONG AS IT IS RELEVANT TO THE ARGUMENT)

GRAPHIC LANGUAGE HAS THE CAPACITY TO STOP US IN OUR TRACKS, OUTRAGE OR AMUSE US, DEPENDING ON THE CIRCUMSTANCES

I LOVE CREATIVE SWEARING

ARE YOU FUCKING KIDDING???

I'D RATHER KILL MYSELF THAN LIVE LIKE THAT - WITH NO PLAN, EARNEST BORING WIFE AND NO FUCK-USELY KICK IN THEIR NITROUS FOOTBALLERS' HISSANT

OF COURSE I'M 'FUCKING KIDDING'

NOW I SUGGEST YOU LEAVE THAT SPERNOCK, GO HOME AND HAVE A CLASS OF WINE

ER, BOLLOCKS

ALSO KNOWN AS COMICS ARTIST 'THOM FERRIER'

I SEE IT AS PART OF THE RICH TAPESTRY OF EVERYDAY SPEECH AND I INCLUDE IT IN MY COMICS FOR THE SAKE OF VERISIMILITUDE









I THINK HOW YOU REACT DEPENDS ON A NUMBER OF FACTORS



SO I TOLD HIM: YOU NEVER GAVE A FUCK ABOUT MY FEELINGS, SO WHAT DO YOU EXPECT?

TEE HEE HEE



INCLUDING THE PHYSIONOMY, ATTRACTIVENESS AND ERUDITION OF THE 'SNEER'

IT MIGHT ALSO DEPEND ON YOUR PERCEPTION OF THE CULTURAL BACKGROUND, SOCIO-ECONOMIC GROUPING, OR EVEN THE RACE OF THE PATIENT, AS WELL AS WHAT SORT OF DAY YOU ARE HAVING, AND WHETHER WE ARE IN THE MOOD FOR AN ARGUMENT



THEY'VE STOPPED MY FUCKIN' MONEY COS THEY SAY I'M FIT FOR FUCKIN' WORK

LESS OF THE 'LANGUAGE' IF YOU DON'T MIND

WE ALL HAVE PREJUDICES, ACKNOWLEDGED OR NOT, AND OUR FEELINGS TOWARDS THE PATIENT WILL INEVITABLY PLAY A PART IN HOW WE RESPOND. PROFESSIONALISM IS ABOUT MODERATING ONE'S OWN REACTION TO FEELINGS EVOKED BY THE CLIENT



STRONG LANGUAGE CAN ARISE AT TIMES OF EMOTIONAL DISTRESS



BUT WHY DID SHE HAVE TO FUCK HIM? (SOD)

JUST LISTEN TO THIS POOR SOD...



YOU WOULDN'T HAVE THE HEART TO PULL HIM UP ABOUT HIS LANGUAGE, WOULD YOU?

WITH THE EXCEPTION OF A FEW, ERM, 'CHARACTERS', IT WOULD SEEM UNLIKELY THAT HEALTH-CARE PROFESSIONALS DO A LOT OF SWEARING IN FRONT OF THEIR PATIENTS. THERE MAY BE OCCASIONS, HOWEVER, WHEN WE 'JOIN IN' IN MIMICKING THE PATIENT TO STRENGTHEN THE RAPPORT...



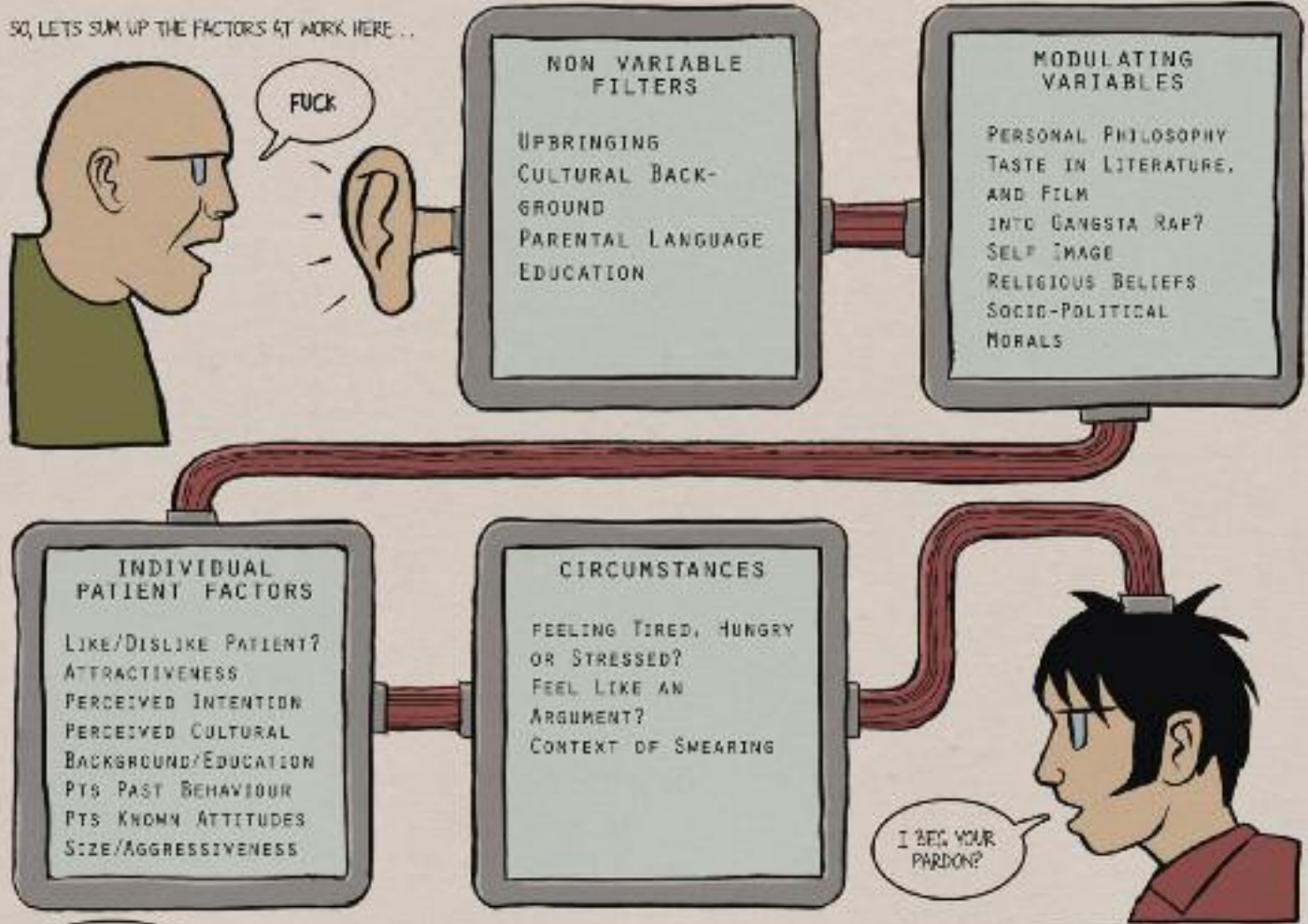
SHE'S KILLING ME, I JUST WANT TO TELL HER TO 'FUCK OFF'

WHY DON'T YOU TELL HER TO 'FUCK OFF'?





SO, LETS SUM UP THE FACTORS AT WORK HERE ...





# DELINEATING DISEASE

Lucy Lyons

*Nothing is more difficult than to know precisely what we see.*

—MAURICE MERLEAU-PONTY

How might drawing, as a phenomenological activity that evinces experience, communicate knowledge about disease? How might its unique requirements of time, observation, and action lead to greater insight for the drawer, greater dignity for the patient, and greater understanding for the public? As a visual artist and academic, I have sought to answer these questions through a decade of artistic research in the medical sciences. In 2005, I was fortunate enough to work alongside the head of conservation at the Royal College of Surgeons of England, where he was about to embark upon the preparation of two donated bodies with a rare disease called Fibrodysplasia Ossificans Progressiva (FOP), a disorder that causes connective tissue to turn into bone. This essay describes my encounters with FOP in historical photographs and illustrations, in skeletons and in the two donors at the Royal College of Surgeons, and finally with patients living with the disease.

FOP is a very rare congenital disorder, affecting about six hundred people worldwide, in which connective tissue turns to bone both spontaneously and through trauma. A secondary skeleton, formed from heterotopic bone (bone out of its proper place), grows and joins up with another area of bone, permanently locking the person within a bony prison. The only visible clue to diagnosing a child with FOP is that usually the patient has malformed great toes. The condition is so difficult to examine and to treat because both diagnostic investigations and treatments involve tissue trauma of some type. Medical interventions thus exacerbate the condition they are meant to relieve.

In investigating the specificity of experiences of this particular disease, I was led to see how drawing could offer a different form of examination, one that captured a greater breadth of experience. After spending years investigating anatomy, I knew I was not interested in standard models or how things *should* look, but in the uniqueness of each encounter I had with disease itself. Through my research, I have concluded that drawing reveals new insights into disease and experience—while maintaining, and perhaps enhancing, respect for both the patient and the phenomenon.

## Historical depictions of FOP

“The woman who became as hard as wood”: this first description of FOP can be found in a 1648 letter from French physician Guy Patin. Images of FOP are hard to come by. Other than medical journals, the only historical visual information depicting people with FOP has come from images of people described as ‘Living Skeletons’ exhibited in circuses and freak shows, two of whom, Jonathan Richardson Bass and Claude Ambroise Seurat, are the only ones depicted in drawings.



**Fig. 1**

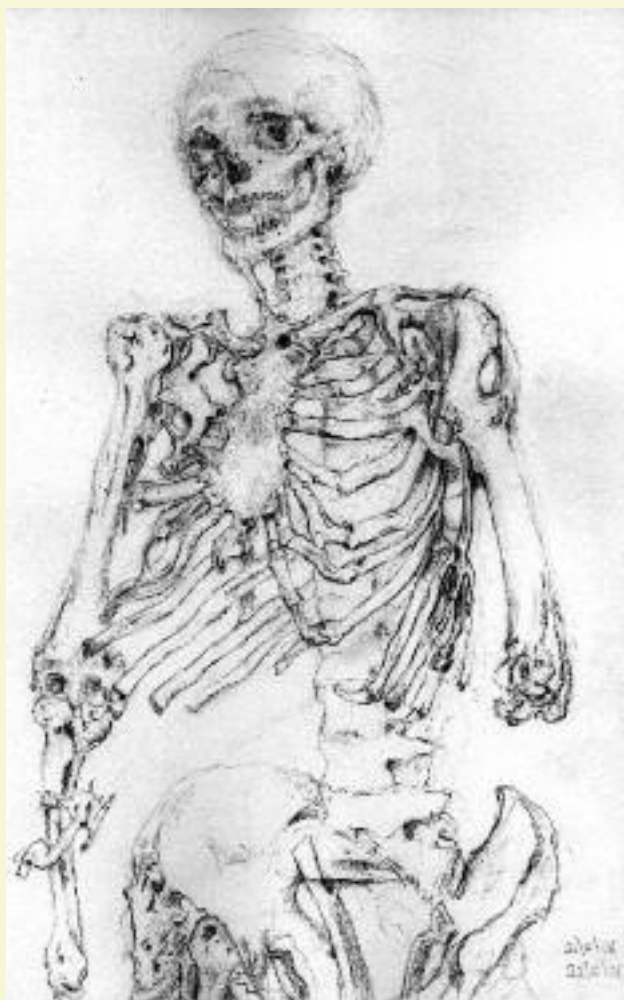
This is the exhumed skeleton of Mr. Jeffs, who was 39 years old when he died. The surgeon George Hawkins kept the skeleton in his collection. When Hawkins died in 1783, John Hunter bought Mr. Jeffs' remains for 85 guineas; the skeleton remains on display at the Hunterian Museum at the Royal College of Surgeons of England.

The secondary skeleton is extremely complicated. It has grown out from the right clavicle and shoulder blade and around the right arm, and then curls across the back, dipping down around the spine then back around the left shoulder before continuing down to a complex bony network across the sacrum. Another main area of heterotopic bone starts at the right hip and curves dramatically back out and then downwards to bridge with the right femur. The already intricate normal skeleton has connected to and is encased by the heterotopic bone, but remains visually separate.

I began drawing the secondary skeleton using a much darker, heavier line. That choice developed as a natural system, clarifying the visual information without altering the data or making a composite. By picking out the relevant detail and changing emphasis on weight of line, I began to present my understanding of the visual experience of the phenomenon encountered.

Claude Ambroise Seurat was born in France on 10th April 1797, and by ten years old he was feeble and revealing his skeletal form. He was reputed to have a very weak and shrill voice (Gould and Pyle, 1897, p. 364). Spanish artist Francisco Goya's bold charcoal sketch of Seurat from 1826 is a remarkable example of an FOP sufferer. Seurat is portrayed standing alone, supported by a walking stick, his thin legs and arms devoid of muscle. He appears to be isolated and vulnerable. His neck and left arm reveal evidence of ankylosis and there seem to be deformities in his hands.

The English illustrator George Cruikshank's drawings of Seurat are collected under the title, *'Living Skeleton (The An Account of that Most Extraordinary Phenomenon called the Living Skeleton, Claude Seurat, now Exhibiting at the Chinese Saloon, Pall Mall, etc.)'* in William Hone's *Every day book* Vol. I. (Hone, 1826). Evidence found in these drawings shows major skeletal abnormalities, including deformities of the scapula and a short, broad neck (both signs of FOP). Seurat's arms appear to be fixed in a slightly raised position. Unfortunately, neither artist made images of his feet, although there is a description that indicates a malformation of the great toes.



**Fig. 2**

In Naturhistorisches Museum in Basel I discovered two more FOP skeletons. After drawing the first skeleton from the back view, I began to draw the view from the front. Expecting the back to have been the more dramatic and clinically useful angle due to the nature of the path of progression of the disease, I was shocked by what I saw in the front. A spur had grown from the lower jaw and bridged with the top of the sternum, effectively locking jaw to chest. This person's mouth had been fixed permanently partially open, the head completely immobilized.

This new experience demanded that I make the numerous marks that appeared around the skull. They are a record of the frequency I observed and had to re-adjust lines to more precisely convey the complexity and detail of the ossification that had occurred. It was difficult to comprehend the effect of this disease on the living body.

Another 'Living Skeleton,' Jonathan Richardson Bass, was born in 1830 and was known as the 'Ossified Man' and the 'Stone Man.' He was first exhibited as the *'Living Wonder of the Age, the Ossified or Bone Man'* in 1887. Anonymous illustrations depict Bass from the front and the side (Gould & Pyle, 1897, p. 787). Despite being very small, these minutely crosshatched drawings clearly show the deformities of his big toes.

Significantly, these early drawings serve two purposes: they reveal the artists' experience of the sufferer, and they have been used by clinicians to make diagnoses of FOP (Hooper, 1992).

## Drawing as a research methodology

The effects of FOP are shocking, almost beyond imagination. When I first encountered an example of FOP I could not understand what I was seeing until I began to "draw my way into it," realizing nothing was how it first appeared. The confusion of excess bone was visually difficult to interpret, even more so when presented as a photograph, which tends to flatten objects and make them tonally indistinct.

Unlike the scientific model, drawing as a research methodology is presented from the first-person point of view and focuses on relationships that develop both between drawer and object and between drawing and viewer. The emphasis is on coming to understand a phenomenon through the activity of drawing it. In the close attention and time it demands, this method engenders dignity as it produces knowledge; it also creates intimacy and preserves difference.

To examine the specificity and breadth of disease I developed a system of drawing I describe as *delineation*. This system is grounded in the act of drawing something directly, without codifying or generalizing the data. It privileges specificity over generic models, and is less concerned with causal events than with understanding the subject within a phenomenological framework. At the heart of phenomenology is "is how we observe and reason and seek to explain phenomena we encounter in the world" (Smith, 2003). The aim of delineation is to record both the object and the delineator's experience of it. It goes beyond acknowledging the object's presence and becomes part of the experience of "living it," connecting the experienced thing and the experiencing person. A delineation is overt in laying bare the experience of its own making as its marks are inscribed, removed and smudged. That transparency invites viewers to recognize it less as an object than as a reminder of its making, or as a record of process.

## Delineating FOP—historical specimens

Unlike images of a shocking object, delineations can reveal detailed and continuing phenomenal aspects of the condition, and can accommodate idiosyncrasy and nuance. Their emphasis on the individuality specific to each encounter dignifies the donors, the people with FOP, and the specimens. No additions or embellishments are made to the delineations and the drawing activity presents explicitly visual experiences of a human condition.

(continued on next page)



### Delineations of donated cadavers

The majority of my research investigating the breadth of FOP involved examining the process of preparation of two donors—66 delineations were made in total. Gradually my understanding of different tissue types became more and more clearly defined.



**Fig. 3**

The twists and dramatic spurs of the FOP bone are portrayed very clearly in the second donor. The point of focus is a large spur that has twisted and bridged across the back under the right scapula. It is recorded as emerging from the skeleton and forms a bridge from the upper arm to the rib cage, spreading and locking over her spine. These exact, clear lines contrast with the softer swirling lines that record the tissue still surrounding some parts of the body. The precision and weight of line used in this delineation provide visual information about my encounter with FOP, and convey the terrible consequences of the effects of FOP.

Although the donors appeared less human as preparation continued and more flesh was removed, I felt I knew them more as the secrets of this dreadful disease were revealed. The more flesh that was scraped away, the more was revealed. The more I drew, the more I understood. The drawings recorded this process, conveyed my experience of it and demonstrated the cumulative collection of fugitive experiences.

### People with FOP

When we encounter illness, disease and difference, usually one of two things occurs: either we stop and stare in horror, aghast, or else we turn away quickly, not wanting to see, afraid that by looking we may ourselves somehow be tainted by another's illness or disease. Delineations offer a third way, enabling patients to make a choice about how they want to be seen.

I asked living patients who participated in this research to decide where and when they would like to be drawn. I visited P in his home. To walk into the home of a stranger with a progressive congenital disease, you cannot expect to be able to just draw them instantly; a relationship has to develop. I did not begin to draw P until he felt comfortable with me being there. When I did draw him, I could see clearly that he had a broadened neck, rigid from fusion, and extra bone visible beneath the skin of his shins. He then allowed me to draw his feet. As his ankylosis prevented him from bending, I had to remove his socks for him. This was a very intimate moment: I was removing the clothing of a man I had only just met, and he too was vulnerable, relying on me and entrusting me with a very personal task. After I drew his feet, I put his socks back on for him.



**Fig. 4**

The deformities in his big toes are plainly visible. This is significant diagnostically as the malformation of the big toe is still the first indication that a person has FOP. The lines of the delineation retain a softness that is appropriate to embodying a sense of living flesh. Lighter lines reveal further deformities and the hard, thick toenails are drawn with a heavier, thicker line. The depiction of lower legs lends the delineation a sense of isolation and vulnerability.

These drawings are the contribution of living patients, their stories overlapping with mine, and I hope they convey genuine feelings of empathy and dignity. Both P and K (fig. 5) have said that they enjoyed the experience of someone spending time looking at them, and were so pleased with the resulting portraits they asked for copies.



**Fig. 5**

I had drawn K the year before, but sadly in 2006 she had fallen and broken her leg. When she was hospitalized, she asked if I would come and visit as she wanted me to draw her. It was an incredibly hot and humid day when I went to see her and the hospital had no air conditioning, only electric fans. K was in a separate side room. She was propped up on lots of pillows, her bed tilted almost to sitting position and she wore her blonde wig with a pretty blue slide. I spent the day with her, drawing and chatting. When shown the finished drawing, her mother said I was the only other person who could see how very beautiful her daughter was.

## Evidence

*Drawing is a very successful way of bringing out the information about where all the new bone is.*

—PAUL WORDSWORTH, NUFFIELD ORTHOPAEDIC HOSPITAL,  
UNIVERSITY OF OXFORD

Professors Jim Triffitt and Paul Wordsworth, specialists in FOP, have argued that the concentration and focus required in the activity of observational drawing makes it a valuable method for gathering information, preventing important detail from being overlooked. The delineations provide essential visual material as there are very few skeletons available and it is not possible to keep returning to them. The system of delineation also offers a clearer visualization than X-ray or CT scan of the way bone actually joins up, demonstrating for example that the myofascial planes and connective tissue are affected rather than the muscle fibres.

This raises further interesting questions about FOP: where does one sort of bone stop, and the other begin? Why does ossification happen exactly where it happens? Where is the bone growing, and where should experts be looking?

The delineations fulfil the wishes of these donors to aid further research, and also reveal what these patients were going through, highlighting the material effects of FOP as a major process in their lives.

The aim of this research was to examine the role of drawing as a sensitive method that quite literally embodies knowledge as it offers further understanding into a horrific disease.

The inquiry has provided useful additional insight into FOP, including adding evidence to support clinical studies concerning areas of ossification and promoting awareness of a rare disease to the general public. The drawings were exhibited at the Hunterian Museum at the Royal College of Surgeons of England in 2008. As one reviewer wrote, “The detail in each piece is extraordinarily exquisite. However gruesome this disease, these images are not—they display a genuine sense of humanity.”

*Lucy Lyons has conducted research at the Hunterian Museum at the Royal College of Surgeons of England, the Naturhistorisches Museum Basel, and the Medical Museion at the University of Copenhagen.*

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# Addressing Loss and Resilience: Informing Patient Care Through Comic Narratives

Judith Kaplan-Weinger

The role of health care practitioners in helping those who grieve to navigate their new life paths can begin with narratives, those they collect from their patients and their families and friends, and even those they experience in a novel environment: the comics. By experiencing the lives of the characters in comics—by reading and seeing how they cope with loss generated by disease, illness, or death—health care practitioners can learn what it means to possess and demonstrate a resilient identity. They can learn how their own patients and the patients' families and friends deal with loss, and then use this knowledge to construct care that addresses the singular identity of their patients and their family and friends. They can frame their interactions with their patients so as to engender within them strategies and mechanisms for facing loss with resilience. Narratives of loss, whether fiction or nonfiction, when presented in the linguistic and graphic form of comics, give health care practitioners the opportunity to live with and explore mourning remotely but still in a way that (sub)consciously prepares them to address the existent needs of those experiencing loss.

One comic that provides content for an analysis of the role of comics in informing health care practitioners is Lynn Johnston's "For Better or For Worse" (FBOFW), and specifically its storyline focusing on the events surrounding a stroke suffered by one character. The storyline I will discuss can be found in the FBOFW collections *Seniors' Discount* (Andrews McMeel, 2007) and *Home Sweet Home* (Andrews McMeel, 2008). According to Johnston's website, "FBOFW" is syndicated "in over 2000 newspapers worldwide and is featured in 20 countries, in eight languages, reaching over 220 million readers." Johnston's website further explains that the strip "provokes thought and brings a refreshing perspective on everyday family life to the comics page."

## **The Linguistic and Visual Semiotic of Comic Strips: The Nexus of Narrative, Loss, Mourning, and Identity**

Writing of "mourning as a process of meaning-making", Neuman, Nadav, and Bessor explain the discursive practice of mourning. They write, "If language is the bridge, then the semiotic aspect of mourning (or the way mourning is mediated by signs), rather than being an epiphenomenon [secondary] or a functional tool for the work of grief, is a sine qua non [indispensable] of the mourning process. ... This semiotic approach suggests that in order to understand mourning, we must carefully study how people communicate their mourning by linguistic [and other semiotic] means" (2006:1373).

The participants in the FBOFW narrative of loss are members of a family, each of whom we observe experiencing a loss of normalcy in the context of the stroke suffered by their husband, father, or grandfather. Reactions to his stroke by Jim himself; his wife, Iris; his daughter, Elly; and his granddaughters, Elizabeth and April, demonstrate construction of various mourner identities, of their respective needs, and of their growing resilience.

Elly is the central character in FBOFW. It is she to whom we are drawn as she centers her life in the midst of her elderly father, and her husband, children and friends. In her role as daughter of Jim, wife of John, mother of April, Elizabeth, and Michael, grandmother, and friend, Elly is variably positioned as she experiences her father's stroke. The linguistic and visual texts position Elly in words and pictures that both denote and connote her identity as concerned daughter, secondary caregiver, involved wife, mother, and grandmother; and, in the context of her father's stroke, one who can guide others through loss and mourning and toward resilience.

As the character around which all stories center, Elly exemplifies Berger's concept of the comic book hero who "must be tested, symbolically killed, and then reborn, with a more profound knowledge of reality" (1973:151). Lynn Johnston says of her: "Elly Patterson has many titles in life—Loving mother and wife, doting grandmother, understanding mother-in-law, devoted daughter, sensitive friend, patient pet owner and retired former business-woman.... Never losing sight of what's important, Elly always makes time to sit and chat over a steaming coffee with one of her many friends, sharing some of the losses and victories on the battlefield of life" ([http://www.fborfw.com/char\\_pgs/elly/](http://www.fborfw.com/char_pgs/elly/)).

In the strip that follows, the reader/viewer finds Elly attempting to balance her life and her responsibilities as she negotiates footings of mother, daughter, caretaker, and mentor, as she cares for others and tries to continue caring for herself. In Strip 1, Elly explains Jim's stroke and what can be expected as he recovers to her youngest child, April. The reader/viewer attends to this frame voyeuristically, being drawn first into the hospital through a funnel of commitment and then, placed at social distance from the family as they gather in the hospital soon after Jim's stroke. It is Elly whom April asks for information and it is Elly who responds. The vector between Elly and April, as well as the distance between them, Elly's placement of her grasped hand on April's shoulder, their exchange of a hug, and the shadowing of John (April's father and Elly's husband) and of Iris, make their mother-daughter/mentor-protégé relationship salient. The final frame exhibits how members of a family, while sharing in loss, cry out for their specific needs to be met and, therefore, require centered attention and coping strategies.





Strip 1

As the stroke victim, Grandpa Jim is positioned as one who handles his stroke and resulting physical and speech therapy with determination, frustration, humor, and appreciation while thinking about the past and trying to incorporate as much of that past into his current life. In the following strip, we see how his communicative contributions (much of them presented nonverbally or in thought bubbles to represent his difficulty speaking following his stroke) and his physical actions reflect his positioning.

In this first strip after Grandpa Jim has returned home from the hospital following his stroke, we come upon him in the foreground; his wheelchair and, therefore, his disabled position are salient. With his back toward the viewer, Jim leads our eye to the door through a funnel of commitment. At the door, Iris greets Elizabeth who is about to enter for a visit with her grandfather, as is the viewer. In the second frame, Jim is centered between Iris and Elizabeth as the focus of their discussion and of their interaction with

one another. His slight smile suggests he is happy to see Elizabeth, and his vector toward her suggests he is listening to what she is saying, although, as we learn, not yet able to interact verbally with her. In the third frame, Elizabeth places herself at eye level with her grandfather connoting they share a connection, an understanding, are on equal ground; they see eye-to-eye. The viewer learns in the fourth frame that Iris has become Jim's voice. Her stance at a level higher than Elizabeth and Jim suggests her unequal positioning as the care-giver to Jim's care-needer. As evinced by Jim's expression of anger—drawn in brows, slit eyes, frown—and as illustrated by the thunderbolt in a darkened cloud above his head within a thought bubble, Jim is angered and frustrated about his loss of independence because of his stroke's initiation of a loss of normality. At the same time, Iris is consoling, as indicated by the placement of her hands on Jim's shoulders, while Elizabeth reacts with sorrowful surprise as if seeing the anger arising from her grandpa.

The similarity in Jim's and Elizabeth's facial expressions suggests, as do the third and fourth frames, a greater alignment between them than between Iris and Jim.

On the FBOFW website, Iris is introduced as

Jim's second wife, [and as] relatively new to his family yet knows and interacts act with all of them. Since Iris met, and married Jim, her life has purpose again. ... Now she has someone to talk to each morning, someone to cook for (who enjoys her cooking immensely!), to watch movies with, someone to share her life. Iris knew it was rare to find love the first time, but to find it twice in a lifetime was miraculous. Smiling comes so easily and naturally to her that sometimes Jim takes her good humor for granted. Then he remembers sad and lonely times, and her smile melts his heart all over again

([http://www.fborfw.com/char\\_pgs/iris/](http://www.fborfw.com/char_pgs/iris/)).



Strip 2

(continued on next page)



Strip 3

Strip 3 also shows Iris to be the characteristic caregiver. Saturated in shadow in the fourth frame, Jim's doctor and Iris are generalized, representing the iconic doctor who shows concern for caregivers as well as for the patient, and the iconic caregiver who suffers the stress, sadness, and loneliness triggered by both the experience of loss and the demands of her role. These strips reinforce the conflict of identities of those who mourn—resilience has its good days and its bad days.

In Strip 4 below, Iris is positioned as both caregiver and teacher as she interprets the caregiver's role to April. The strips that incorporate April's learning about her grandpa's stroke, interacting with him, and recalling special memories of him, are among the most poignant of the series and most supportive of the influence of loss on the construction of a resilient identity. Iris is coping with and coming to accept Jim's state; she looks left to the 'past' in the second frame as she recounts his doing the same in a variation of a return to the new 'normal'. In telling April of her actions to help Jim, she demonstrates the selflessness that at times has previously been exaggerated for humorous effect. That selflessness now, though, informs April's position as the child learning how to experience and deal with loss. April looks over and leans

toward the shoulder of her mentor as they both focus their vector on Jim's past—his deceased first wife. In the 5th frame, Iris puts her arm around April's back, guiding April away from Jim who, saturated in shadow in the foreground, here represents not the man himself, but the generalized 'ill' whom all of us must learn to cope with. Iris and April share intimate distance; April looks at Iris as Iris looks forward and guides April into a future supported by Iris's knowledge and guidance. Iris' actions are a message to health care practitioners that just as elders learn to cope and demonstrate resilience in the face of loss, they can follow suit and guide other mourners in the development of resilience. Additionally, they speak to the multiple individuals—along with the patient—who are in need of centered care in situations of loss.

### Conclusion

Harvey (1996) contends that “without the pain that comes from significant loss, there can be no story. Without the storytelling, there can be no meaning. Without meaning, there can be no healing” (205). Pointing to the role of texts specifically within the comic genre, McCloud declares, “...when you look at a photo or realistic drawing of a face—you see it as the face of another. But when you enter the world

of the cartoon...you see yourself...The cartoon is a vacuum into which our identity and awareness are pulled...an empty shell that we inhabit which enables us to travel in another realm. We don't just observe the cartoon, we become it!” (36). For health care practitioners, comics presenting characters who are constructing resilient identities in the face of loss offer new indicators of and means for patient-centered care for those who mourn.

*Judith Kaplan-Weinger is professor of linguistics at Northeastern Illinois University in Chicago where she teaches courses and conducts research in discourse analysis, anthropological linguistics, and sociolinguistics. Her current research focuses on the linguistic and visual semiotic analysis of texts of loss, grief, and mourning.*

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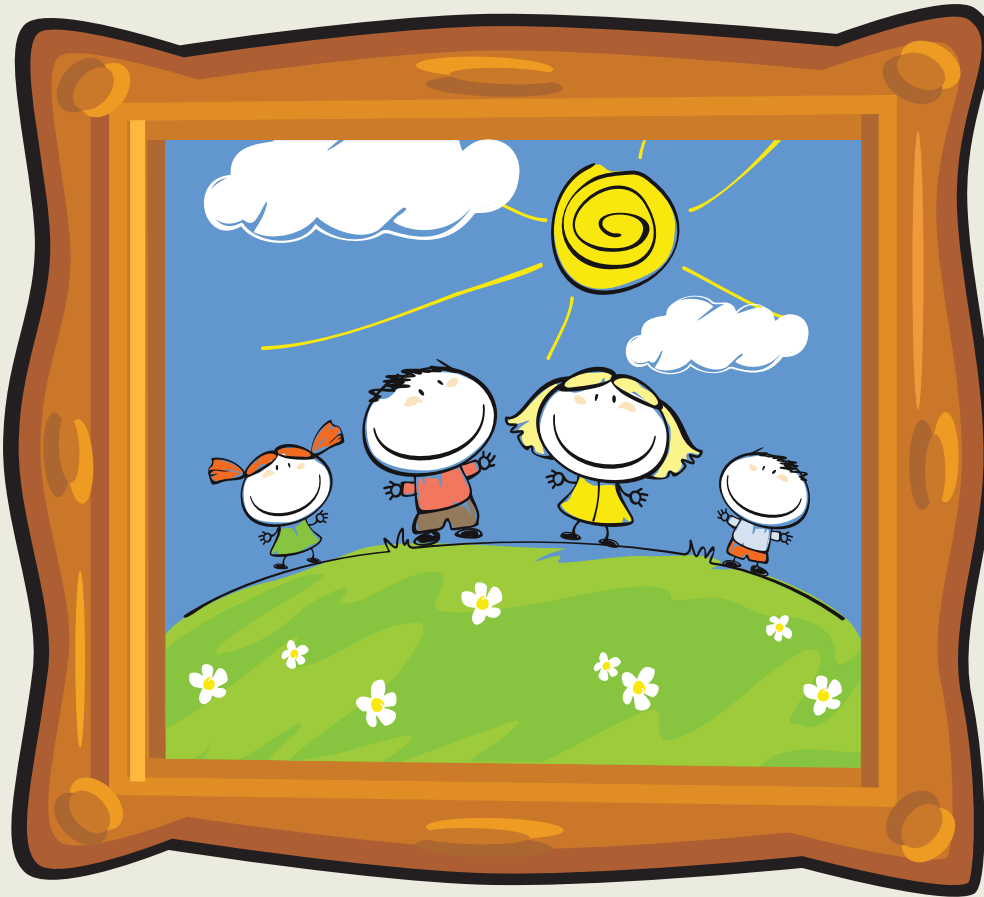
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Strip 4



# The Pharmaceuticalized “Good Mother”



*Michael Oldani*

In the early 2000s the pharmaceutical company Pfizer, Inc., produced a series of comic book-like advertisements that outlined in scripted fashion how a “medical consumer” could obtain a prescription of the SSRI antidepressant, Zoloft (sertraline HCl).

Kathy, for example, is “age 41” and lives in Irvine, California. Although in the last panel of the comic-strip ad we are told that the story is not based on an “actual person,” Kathy is most likely a composite of real patients. The pharmaceutical industry collects drug narratives to create “Kathys”

in their advertisements. There were other cartoon ads that featured “Joanne,” a depressed divorcee and “Cindy,” a depressed office worker. All did very well on Zoloft.

Story gathering occurs by sifting through the written reports of drug reps (doctors love to tell case histories), through patient testimonials published in magazines,<sup>1</sup> through informal web-based networks and blogs, and now the industry can get patient stories, complete with discussions about efficacy and side effects as well as charts of daily drug regimens, by purchasing them directly from websites like “PatientsLikeMe.com.”

The scene-by-scene script of Kathy’s story seems so simple but has remained paradigmatic over time: Kathy is depressed; her daughter recognizes this fact (to Kathy’s dismay), Kathy goes online (and most likely completes a “symptom checklist”), learns about Zoloft, and tells her doctor about it. The physician has also been visually ‘branded’—note the Zoloft ad in the background—and agrees with Kathy’s self-assessment. She can then obtain a written prescription, feel much better, return to normal domestic activities, restore family life to a state of harmony, and, finally, complete the cultural script of the “good mother.”

Pfizer’s marketing division banks on the fact that, consciously or not, consumers understand and accept this gendered script. Moreover, even if we are offended by this particular ad or its gendered theme, advertisers always have their seemingly neutral fallback position: our advertisements simply reflect current cultural norms and represent mainstream aspects of society. However, the advertisement itself is not neutral: it promotes a pharmaceutical product for psychological distress and it locates the source of this distress within a woman’s neuro-biology. If you cannot be a “good mother” who fosters a happy home, then a pharmaceutical prescription is the commonsense, everyday option—*the norm*.

*(continued on next page)*

### Plotting Prescriptions

Margaret Mead, the famous American anthropologist, interrogated gendered norms at home in the U.S. and abroad (most notably in Samoa) and her insights remain helpful when thinking about the pharmaceuticalized notion of the good mother. In particular, she explored the “cultural plots” behind human relations.<sup>2</sup> These plots, or what I refer to as “scripts,” revolved most often around sex-gender roles: societies have developed “parts” for their participants to play out that structure how one should act over a lifetime. These gendered scripts outline particular roles for individuals to inhabit: “woman,” “man,” “mother,” “father,” “wife,” “husband,” and so on. Stray too much from the ideal role and you risk all sorts of scrutiny, ranging from gossip to social ostracism. Your best shot at cultural survival is role-conformity or the formation by your society of alternative types of roles for one to inhabit (“stay-at-home dads,” “working moms,” etc.) In the end Mead’s agenda was very clear: one must observe what she described as “dramatized sex-difference” across cultural groups in order to differentiate between social constructs and the biological facts of sex-gender.

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The pharmaceutical industry continues to play a tricky game with doctors and medical consumers, conflating gender, culture, and biology into a single, coherent narrative.

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As a medical anthropologist, I first began to use Mead’s insights when observing clinical encounters between doctors and patients and seeing the effect of sex-gender differences on pharmaceutical prescribing. Women and men talked differently about psychiatric medication, in terms of their willingness to take a prescribed medication or to have it prescribed for their children. A consistent cultural script that emerged during my observations constructed psychiatric medication as “mother’s little helper.” This phrase has a deep history and was immortalized by the Rolling Stones in their song “Mother’s Little Helper,” alluding to Valium (diazepam), a bestselling tranquilizer for women in the 1960s. But the merger of these two scripts—the pharmaceutical prescription and the cultural plot—goes much further back. In fact, you can see images in medical journals of distressed mothers in domestic settings (or even women surrounded by floating symbols of domesticity, such as vacuum cleaners and ironing boards) in advertisements for psychotropic medication starting in the 1930s. The medical historian Andrea Tone notes that both men and women were prescribed benzodiazepines and barbiturates as gender-neutral ‘helpers’ during the post-World War II era (the tranquilizer Miltown was called “executive Excedrin” for men). These drugs were encouraged and accepted in order to treat our collective nerves, frayed by cold war anxieties, and to enhance productivity, both domestic and outside the home, as the U.S. began to compete globally as an industrial force.<sup>3</sup>

Beginning in the 1970s, the cultural script of drugs as ‘little helpers’ shifted predominantly to the domestic space and pharmaceutical ads focused mainly on women. This cultural script continues to be recycled in and through the latest and most hyped, branded psychoactive medications in the medical marketplace: In the 1980s Xanax (alprazolam) was inserted into the script; in the 1990s the SSRIs—from Prozac (fluoxetine) to Celexa (citalopram); in the 2000s it was the stimulants like Adderall (dextroamphetamine and amphetamine). Today, it’s the SNRIs, such as Pristiq (desvenlafaxine) as well as atypical antipsychotics, like Abilify (aripiprazole), that are the latest helpers. A consistent mega-market remains the “mood stabilization” of women, a pharmaceutical industry-coined term turned medical diagnosis, which translates to treating anxiety and depression in various forms.<sup>4</sup> Today, polypharmacy is common and becoming routine for many women (for example, atypical antipsychotics as “add-on” treatment for depression). The good wife and mother script remains constant, while women more generally continue to be the face of psychotropic drug promotion. (One exception is schizophrenia, a more limited market, where men remain Big Pharma’s target.)

In view of this personalization of the female psychiatric patient, it may seem puzzling that in the early 2000s Pfizer chose to produce a series of graphic ads for Zoloft with a near-faceless, almost gender-neutral, animated character (“Kathy” is gendered ever so slightly by the curve of her lips). Wanting to know more, I tracked down a Pfizer drug rep in 2005 who told me that the characters in all of these graphic ads were generically referred to by managers and marketers as “Dot.” This name was also used when promoting Zoloft to doctors using graphic comic visual aids, and Dot was central to a series of patient education materials that explained the neurochemical basis of mood disorders to patients prescribed Zoloft. (In those images Dot looks like it could have been derived from cutting off the rounded end of the dendrite also illustrated in the ad.) The drug rep added that Dot was “really effective” in getting doctors’ attention. Even pharmaceutical advertisers I interviewed during a workshop at the University of Minnesota’s Center for Bioethics conceded that this specific comic



campaign was “simple yet highly effective.” They envied Pfizer. These advertisers were also very keen on the gendered component of the graphic ad, indicating to me that the “good mother” script is well known within advertising circles.

I have to confess that I helped contribute to the genealogy of the pharmaceuticalized good mother in the 1990s when I too was a drug rep for Pfizer. We were instructed by management to promote Zoloft for “depressed soccer moms.” We did also try to promote Zoloft for “coach potato dads,” but this story never resonated with prescribers in the same way. It seems that a good, culturally embedded and visually scripted narrative trumps all else. With Dot, we get it by *getting less of it* (I am willing to bet that most readers struggled to finish the word-for-word side effects information below Kathy’s Story). In the end, the ad remains ‘generic’, yet you can easily insert yourself, or someone you know, into the branded script, which reflects our collective, cultural common sense, especially in the U.S.

### Profitable Sexism

Big Pharma gets it too, because the industry does intensive cultural homework. Drug manufacturers continue to wink at medical consumers and doctors while profiting greatly from these recycled cultural scripts, in large part because there are *very few alternative cultural plots* available. This is highly disturbing on several levels. First, Big Pharma has managed to encapsulate the female consumer into a particular psychiatric narrative for over eighty years: she needs prescription psychotropics to be her little helper. Second, this has helped to script very limited ways of caring for, and thinking about, mental distress and culturally abnormal behaviors. Third, as “Kathy’s story” illustrates, this cultural script is based on a flawed view of mental illness: that it is caused solely by biological abnormalities that can be cured only by pharmaceuticals. And finally, psychopharmaceuticals and these accompanying cultural scripts, underpinned by a simplistic, yet profitable, biological determinism, now circulate globally. It is clear that the prescribing and profit targets of women have been met by the “psycho-pharmaceutical industrial complex.” The dollar numbers are staggering. Beginning in the 1980s the market for psychotropic drugs has grown from \$500 million to over \$20 billion annually just in the U.S. alone.<sup>5</sup>

However, as psycho-pharmaceuticals circulate globally and are prescribed in new locales and within differing cultural milieus, drug and cultural scripts collide in unpredictable ways, creating new domestic dramatizations. This may ultimately help doctors, patients, and scholars scrutinize and unravel the connections between pharmaceutical scripts, cultural plots, and the neurochemical basis of mood disorders. In the meantime, these collisions can be volatile. Stephan Ecks, a medical anthropologist working in India, documents how there a mother, being “good” by seeking pharmaceutical treatment for her son’s ADHD, may be recast by her family, specifically her husband, as being the “sick one,” literally a *bad mother*. The son’s psychotropic medications are stopped and the mother is removed from the house, often placed in psychiatric care and medicated against her will.<sup>6</sup> In this extreme example, we see how the domestic scene can be a disturbing battleground of culture, pharmaceuticals, and power.

Yet even in this example the prescribing of psychopharmaceuticals is not eliminated *per se*, but shifted from child to mother—powerful drugs circulating among vulnerable individuals. It may only be a matter of time before India (and other countries) embrace the merger of psychopharmaceuticals and North American cultural scripts. Yet, as troubling as Eck’s case is, it forces us to ask why specific, highly gendered plots in the U.S. continue to be promoted and embraced, emplotting real and fantasy persons through advertisements, websites, drug rep talk, and expert discourse. The pharmaceutical industry continues to play a tricky game with doctors and medical consumers, conflating gender, culture, and biology into a single, coherent narrative. For millions of people, Kathy’s story is not at all disturbing or limiting in any way; rather, it’s understood as liberating, even salvific: a vivid, scene-by-scene portrait of what everyday reality can be, an instruction manual on what it takes to be a good mother.

Michael Oldani, PhD, MS, is Associate Professor of Medical Anthropology at the University of Wisconsin-Whitewater. [oldanim@uw.edu](mailto:oldanim@uw.edu)

<sup>1</sup> See G. Sealey. 2007. “What every woman should know about antidepressants.” *Glamour*. November: 137-148.

<sup>2</sup> Margaret Mead. 1935 [2008]. “Introduction to Sex and Temperament in Three Primitive Societies.” In *Anthropological Theory: An Introductory History*. R. McGee and R. Warms (eds.). New York: McGraw-Hill. p. 222.

<sup>3</sup> See A. Tone. 2009. *The Age of Anxiety: A History of America’s Turbulent Affair with Tranquilizers*. New York: Basic Books (Chap. 7).

<sup>4</sup> See D. Healy. 2008. *Mania: A Short History of Bipolar Disorder*. Baltimore: Johns Hopkins Press.

<sup>5</sup> B. Levine. 2008. Psycho-Pharmaceutical Industrial Complex. *Z Magazine*.

<sup>6</sup> S. Ecks. 2009. Polyspherical Pharmaceuticals: Global Psychiatry, Capitalism, and Space. In *Pharmaceutical Self: The Global Shaping of Experience in an Age of Psychopharmacology*. J. Jenkins (ed.). Santa Fe: School for Advanced Research Press: 97-116.



*The Doll's House* (Sandman Vol. 2) © DC Comics. Used with Permission.

# A Sustaining Graphic

Iain Perdue

Graphic is many things. It's a visual sensory experience that conveys information. A graph or image that better elicits something the text describes. When it's overwhelming, disturbing our memories, disrupting our normal actions, it's graphic. It can also be, as I will explain, a fertile catalyst for research. It causes interrogation of the research experience, in this case the social connections by which illness is displayed and transmitted, and of how that experience is refined and recast for dissemination.

As a medical anthropologist, it's my job to seek out qualitative differences recounted by people in the space between their knowledge of an illness, care providers' models of disease, and the lived experience of people. In so doing I engage with the intersection of health care and certain distinct permutations of what is graphic. Illness is graphic beyond just the visual encounter. I don't see the bones, blood, vomit, and putrescence of certain diseases, but I do experience the recounting of personal tragedy, abuse, rape, malice, and institutional structures that hinder recovery. It is no less graphic for existing intersubjectively.

During recent fieldwork, I spoke to people with depression in northern England. I spent many hours with almost fifty people, interviewing them repeatedly over the course of two months, often in their homes. This means people coming in and out, children needing feeding, televisions running, phones ringing, tea being brewed, biscuits being offered—in short being a part of the quotidian experiences that an anthropologist must see in order to understand how people live their lives. Depression is distressingly common, and extremely intractable when it

presents chronically. In discussing it, personal tragedies, family horrors, and my own concerns for and about these people all emerge. I recount here one ethnographic vignette that depicts how other forms of graphic intercede in my work.

*I cycled to the next participant's address. This area was new to me, an empty mixed-use section just south of the city, a place where you rarely saw people on the sidewalks, and though it was close to the touristy areas, relatively barren. Plucking my appointment book from my backpack after locking my bike to a tree, I checked the date, time, address, and phone number for Richard, my next participant. Apartment 33A. As I wandered through the blocks of flats I considered that they were likely council housing. It's hard to judge by architectural exteriors alone, but they had a semi-stale ambiance, a partially vacant feel, with dusty chintz curtains and ambivalent maintenance. Finding the buzzer I pressed it.*

*"Hello?"*

*"Hi. It's Iain, from the University. I'm here for our three o'clock interview."*

*Bzzzz.*

*I climbed a dank stairwell with stained cement floors. Partially exposed to the elements, debris crowded into the corners where the walls met. It had been my experience thus far, when faced with a new participant's door, that you just could not anticipate what someone's home looked like.*

*"Iain! Yes, hello. Come in, come in. I'm Richard." He was late forties, large, genial and had a morbid sense of humor that was readily displayed throughout our interview. I extended my hand.*

*"Pleased to meet you Richard. Thanks for agreeing to be interviewed for the project."*

*"Not at all. I don't get many visitors. Even if they're just here to probe my mental state."*

*Like I said, humor.*



*The flat itself was dark and smelled of cat piss. I felt uneasy as I sat down on a dingy brown couch, sun bleached near the curtains and covered in cat hair. He used to be involved in the funeral business and had actually embalmed members of his own family after their death, he told me as our interview progressed. As I sat there asking questions, my eyes slowly adjusting to the low light levels, I realized he reminded me of someone. He was seated in a recliner of a different era than the couch, also near the window, but having the curious effect of shading his face slightly, casting a rather sinister pall. I had asked the demographic questions, and began to get to the meatier ones on how his treatment had gone, when his corpulence finally alerted me to the individual he reminded me of. I am a voracious reader. I don't confine myself to any genre or time period. Several years before, during an ill-fated relationship, I was brought into contact with a series of graphic novels. In one of the foundational works of the genre, Neil Gaiman's Sandman series, the protagonist Morpheus encounters a man who is taking part in a Cereal Killer convention (a cute literary trick I was amused with when I read it, and which stuck with me). Richard reminded me of one of the killers, a character who abused and slaughtered children, a man called Funland. Throughout our interviews this image remained.*

This contamination of emotional states from my past to the present is part of research. Being a good researcher and writer—whether clinical, qualitative, anthropological, or otherwise—means being reflexive, or aware of how my position, attributes, questions and interpretations affect my research and my relationships with my participants. Our society regards older men who live alone with little financial means as threatening. (Picture Richard as I have described him; now picture him wealthy with all its trappings and see if your opinion changes. He appears more benign, doesn't he?) I had several times considered how in a place as health-and-safety mad as Britain, I, as the only fieldworker on the project also had the only real knowledge of where I was going, when, and with whom. My safety was not assured, though I was relatively convinced I could handle anything that came my way. With Richard certain aspects of his behaviour were highlighted to me because of my concern. I accepted an offer of coffee because hospitality cements the bond between us and helps break down the interviewer/researcher and interlocutor/participant barrier that can hinder resourceful dialogue about treatment and experience. Then I wondered idly if he had put something caustic or soporific in my coffee. I did not wonder the same thing when I accepted tea and biscuits from the matronly retired school teacher later that same day, a woman who would leave cheerios on the carpet for her grandson to vacuum up because Pooh-bear had been messy and he adored helping Pooh. I still drank Richard's coffee, though.

The (seeming) inappropriateness of this image, Funland as Richard, has sedimented him into my mind. The collusion of his story about his history and treatment; his loneliness and his morbid sense of humor; the beatings he endured and the purpose his life was given by teaching seniors computer skills; and the revulsion I have for Funland nestled in my feelings about *The Sandman* books and what they mean to me: these created a graphic encounter. It depicts how transference operates in research, but also my own concerns about being an autonomous researcher visiting depressed individuals in their homes at all hours of the day. The graphic interceded in my research and in so doing I was reminded of the social isolation and judgment an individual like Richard would face. In this way I return to his story, my data, with ideas and questions about the forces shaping his illness experience. My incorrigible imagination was a fecund spot for generating questions about his experience. I am part of what society has made me, and even if someone else would not exactly picture Funland, Richard's weight, online dating, poor living conditions, and depression would be ample grounds for others to view him harshly.

My exploration of a graphic encounter must necessarily end with something written. For what are letters but graphemes? Little visual squiggles to which we ascribe meaning. The conventions of any academic text aver that I must avoid the sensational, obscure the identities of those I meet in the course of research, and faithfully provide precise evidence of their personal experiences. How am I meant to translate Richard into writing when I am expected to erode the graphic? I must render my interactions with this space meaningfully and incisively through ethnography. Traditionally this happens in a research monograph articulated around a year or more of participant observation in a specific location. It is a written account rich in detail and social analysis. When written well, it produces a captivating portrait of a community's ethos. When the work is shorter, as this recounting is, one aspect of a community is examined and then represented ethnographically. And so in producing something ethnographic, I render my own graphic experience legible, and place it out in the world, where it too refuses to be subsumed.

**Confidentiality & Consent Disclosure:** I have altered the name of the person depicted in this encounter because the simple resemblance to an abominable character in a graphic novel should not expose him to opprobrium. As the experience recounted is predominantly my own, and his morphology was the primary generative factor in my degenerate imagination, rather than anything he confided to me, I did not seek his permission. In any event, there is no appropriate manner to approach a depressed man and ask if he minds being compared to a particularly prurient embodiment of horrific behaviour without casting the graphic spectre of further self-doubt and castigation. That is the absolute last thing he deserves.

*Iain Perdue began studying health and medicine from an anthropological perspective when he was convinced by an archaeologist at Loyola University Chicago that he should help study magic, medicine, witchcraft and religion in Mexico. He went on to study schizophrenics during his post-grad at Oxford and currently works on a forensic science project that might best be described as examining CSI practice in England.*



Medical Humanities and Bioethics Program  
Northwestern University  
Feinberg School of Medicine  
750 North Lake Shore Drive, 6<sup>th</sup> Floor  
Chicago, Illinois 60611  
[bioethics.northwestern.edu](http://bioethics.northwestern.edu)

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## Alison Bechdel: A Portrait by Riva Lehrer



[Charcoal, mixed media and collage on paper. H30" x W44". 2010]

In 2008 I asked Alison Bechdel, the graphic novelist, to sit for a portrait. Already celebrated for her long-running comic strip, *Dykes to Watch Out For*, Alison really rose to literary attention in 2006 with the publication of *Fun Home*, her graphic memoir. It tells the story of her father, a gay man living a closeted life as the head of the family.

Alison and I had admired each other's work for years. Though I am not a cartoonist, we both use our work to explore identity and the struggle for mental health in the

face of societal judgment. We also both had parents who committed suicide. Alison's next book would be about her relationship with the living parent: *Are You My Mother?* We decided to center her portrait on the idea of looking back, through reflection and the shadow of the past. Mo, her autobiographical character from *Dykes*, is faintly embedded in Alison's shadow. Over it is a drawing of her mother at the age Alison is now. We worked collaboratively; I completed the charcoal collage, and sent her a tracing paper mock-up with reserved space for her part. I did not know what she would draw. Once I got the sketch, I hand-transferred it onto the charcoal drawing.

Alison depicted her mother as remote and paying no attention. She focuses instead on the book, which may in fact be *Are You My Mother?* With casual cruelty, a thin slash of cigarette smoke rises from her fingers and crosses out the mirror where their reflections overlap.

*Chicago artist Riva Lehrer is best known for drawings and paintings that explore issues of physical identity, especially regarding disability and the socially challenged body. Her work has been exhibited in venues that include the United Nations, the National Museum of Women in the Arts and the Smithsonian Museum, and appears in a new anthology, Sex and Disability, edited by Robert McRuer and Anna Mollow. She is adjunct professor at the School of the Art Institute of Chicago and teaches a Medical Humanities seminar at Northwestern University.*

Riva Lehrer: [www.rivalehrer.com](http://www.rivalehrer.com)

Alison Bechdel: [dykestowatchoutfor.com](http://dykestowatchoutfor.com)