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PEER-REVIEWED CME ARTICLE: MEDICAL EDUCATION

Roles of Graphic Pathographies in Clinical Training Megan Yu

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Abstract

Although graphic pathographies have recently been recognized as playing an important role in medical care, they have not been formally incorporated in many medical school curricula. In this paper, I discuss current applications of graphic pathographies in medicine as well as some potential ethical and epistemological challenges that can arise when using these narratives. Health professionals and medical educators should understand when, why, and how to use graphic pathographies with the goal of enhancing medical education and patient care.

Origins of Graphic Medicine and Graphic Pathographies

The foundations of graphic medicine can be traced to the evolution of autobiographical comics along with the recent development of narrative inquiry and narrative medicine in the 1980s. Although the quest for discovery of notable medical figures was portrayed as a form of heroism in adventure comics of the 1940s [1], the American cartoonist Justin Green was credited with contributing to the autobiographical comic genre in 1972 when he published *Binky Brown Meets the Holy Virgin Mary*, a reflection on his suffering from a compulsive neurosis [2]. Contemporary narrative inquiry was established in the 1980s by Bruner and Sarbin [3]; Bruner [4] differentiated the scientific and narrative ways of knowing, and Sarbin [5] discussed narrative as "a root organising principle of human activity" [6]. In 2000, Charon formally established narrative medicine as promoting healing in medical practice [7]. However, it was not until 2007 that Williams coined the term "graphic medicine" to refer to the use of comics, including "graphic novels" or booklength narratives, in health care [8, 9]. Such comics provide a continuous reading experience and allow readers to briefly reflect on their values and experiences [8].

Recently, the term *graphic pathographies* (i.e., "illness narratives in graphic form") was coined by Green and Myers to refer to a subgenre of comics that addresses the patient experience of illness [9]. These narratives typically are nonfiction and created either by

patients to reflect on their illness experience or by trainees or medical professionals to reflect on their training or to help patients learn more about their illnesses. Drawing on the principles of narrative medicine, comics and graphic novels allow patients and health care professionals to find meaning in suffering, form better connections, and identify any misconceptions stemming from cultural bias or inaccurate information that might affect the diagnosis and treatment of an illness [8]. For instance, a comic can help patients understand that anxiety symptoms might indicate the possibility of an anxiety disorder and are not merely part of life.

Although graphic pathographies offer many educational and clinical benefits, few empirical studies have evaluated their effectiveness, and medical educators have not widely incorporated them into medical school curricula [8, 10]. This paper explores current applications of graphic pathographies in patient care, medical education, and narrative inquiry. It also addresses some potential ethical and epistemological challenges that might arise when using these narratives in hopes that they might be properly integrated into medical school curricula and clinical care to help patients learn—and health professionals teach—about illness.

Value of Graphic Narratives in Medical Education and Patient Care

Patient care. Graphic pathographies have been used to <u>promote public awareness</u> of various diseases such as diabetes, mental illness, and HIV [11-13]. They are particularly suitable for this purpose as opposed to other media because they illustrate certain aspects of an illness through visuals and text. Combining images and text also allows patients to associate new information with existing knowledge, thereby enhancing visual understanding and knowledge recall [9].

Graphic pathographies have also been used to help patients better understand what to expect from their illnesses and find meaning in their experience [9]. For instance, a physician might recommend that adult patients with type 2 diabetes read *The Mysterious Symptoms: A Story about Type 2 Diabetes*, which follows the character Alicia from the onset of her diabetic symptoms to her diagnosis and the impact of diabetes on her daily life [14]. Graphic pathographies not only allow physicians to explain the diagnosis but also help patients feel more in control of their situation. For instance, diabetic patients experiencing the stress and fear of not knowing how to manage their diabetes might feel less apprehensive once they learn how to take care of themselves by reading *The Mysterious Symptoms*. Images from comics might also evoke certain questions for patients that could help them understand more about their disease. Health information comics also have the potential to support patients in understanding the social and psychological aspects of a condition [10], thereby helping them to gain more insight into their feelings and to interpret their experience. Despite these benefits, studies investigating the effectiveness of comics as patient education tools overwhelmingly

focus on whether comics properly convey the factual information about an illness rather than their narrative content [10].

Graphic pathographies have also been used as tools to promote patient awareness during the informed consent process. Furuno and Sasajima found that 68.8 percent of 16 family members of patients who had suffered from an intracerebral or subarachnoid hemorrhage believed that reading comics about these conditions was useful for understanding the doctor's explanation during the informed consent process, and 93.8 percent of respondents preferred using comics in other medical situations [15]. Another study demonstrated that using multimedia aids, including comics and animated videos, improved participant knowledge scores [16]. While more empirical studies are needed to further evaluate the effectiveness of comics in patient care, these initial findings suggest comics may help patients understand more about their illnesses.

Medical education. Comics have been used to illustrate complex concepts in various scientific courses, such as human anatomy. Instructors have reported that improvement in motor skills, visuospatial skills, writing, and course grades is associated with reading of educational comics [17-19]. Graphic pathographies have also been used to foster narrative competence—what Charon defines as "the set of skills required to recognize, absorb, interpret, and be moved by the stories one hears or reads" [20]—and empathy among medical trainees. Studies have shown that teaching with comics is associated with an improvement in a variety of doctoring skills and attitudes such as empathy, communication, clinical reasoning, and an awareness of physician bias [21-24]. Many comics deconstruct diverse and complex issues in medicine and help trainees cope with profound experiences. For instance, for trainees who might feel overwhelmed when entering their clinical clerkships, comics could serve as useful guides for clarifying the fundamental principles of clinical examination and evaluation. Creating comics also provides medical students the freedom to reflect deeply and honestly about the values that are shaping their emerging professional identities, such as the importance of communication and collaboration [22]. Furthermore, because the visuals in comic drawings can be highly subjective, trainees' drawings could provide medical educators with insight into sources of trainees' dissatisfaction and what they might mean for medical training. However, more empirical studies are needed to rigorously evaluate these potential benefits, as comics have received little attention from health care and bioethics scholars until recently, and the social and emotional impacts of images and visual metaphors in comics are in need of further evaluation [8, 25]. Such studies could possibly encourage more medical educators to integrate comics into medical curricula.

Narrative inquiry. Many studies using comics have primarily focused on the experiences of patients and medical students [21, 22, 26]. For example, some have analyzed the messages expressed in trainees' comics and what they might mean for medical education [21, 27]. Some researchers have also used graphic pathographies to generate

data from patients and health care workers to promote reflective strategies of telling and understanding stories. For instance, Al-Jawad describes how comics provide a "strong narrative thread" that allows trainees to link their clinical experiences with their interpretations of sound clinical practice [26]. Moreover, the visual aspect of comics allows researchers to reflect on the symbols and literary devices being used and to make multiple, reasonable interpretations regarding complex issues in medicine, such as whether illness is viewed as a fight or a burden [25]. Comics can also be used to shed light on the experiences of multiple participants, as physicians, patients, and other health care workers play different roles in the interdisciplinary clinical environment, and each story reveals a different dimension of social professional narratives [28].

Ethical and Epistemological Challenges

As more medical educators use comics to enhance medical care, some ethical and epistemological challenges arise and should be addressed. For instance, researchers collecting comics created by patients and trainees should maintain confidentiality ("the principle of keeping secure and secret from others, information given by or about an individual in the course of a professional relationship" [29]) by obtaining consent from patients and trainees to use their comics before collecting them and not disclosing any details about the comics publicly. Another potential ethical issue is the <u>hierarchical</u> culture of medicine, which has been defined as the ranking of medical professionals "based on level of authority and experience" that creates "constraints concerning who speaks up, when to speak up, and how to speak in order to be heard" [30]. These constraints are often applicable in situations that involve a power imbalance. For example, instructors and medical educators might not evaluate favorably or might punish students who illustrate comics that do not cast in a favorable light the challenges of becoming a physician. In such cases, it might be better to include an evaluator within the medical hierarchy who is both competent and impartial [30, 31].

Additionally, because comics might only illustrate certain aspects of an illness, they should not substitute for meaningful conversations between patients and doctors but rather serve as supplemental instruction about illness [9]. This goal could be achieved by training doctors to use only portions of the comic to describe the diagnosis and elicit the patient's treatment preferences. Physicians should also be willing to arrange follow-up visits and conversations with patients, during which comics should be used sparingly to clarify certain aspects of an illness.

Conclusion

Graphic pathographies have recently been recognized as playing an important role in patient care and medical education. They have been used not only to help medical trainees reflect on the ethical practices of medical care but also to help patients learn more about their illnesses. Despite this development, graphic pathographies have not been widely integrated into medical school curricula. More robust methods should be

developed to evaluate educational comics' short-term and long-term educational impact, and ethical and epistemological challenges should be addressed as more educators use graphic pathographies to enhance medical care. Addressing these educational and ethical challenges would not only establish the potential therapeutic benefits of graphic pathographies in medical care but also promote empathy and reflection in medical professionals and patients.

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Megan Yu is a recent graduate of the University of Virginia and plans to attend medical school. She has interests in narrative medicine, health policy, neuroscience, and computational biology.

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PEER-REVIEWED CME ARTICLE: MEDICAL EDUCATION

Representations of Patients' Experiences of Autonomy in Graphic Medicine Mark Tschaepe, PhD

Editor's Note: To claim one AMA PRA Category 1 Credit^m for the CME activity associated with this article, you must do the following: (1) read this article in its entirety, (2) answer at least 80 percent of the quiz questions correctly, and (3) complete an evaluation. The quiz, evaluation, and form for claiming AMA PRA Category 1 Credit^m are available through the AMA Education Center.

Abstract

I advocate using graphic medicine in introductory medical ethics courses to help trainees learn about patients' experiences of autonomy. Graphic narratives about this content offer trainees opportunities to gain insights into making diagnoses and recommending treatments. Graphic medicine can also illuminate aspects of patients' experiences of autonomy differently than other genres. Specifically, comics allow readers to consider visual and text-based representations of a patient's actions, speech, thoughts, and emotions. Here, I use Ellen Forney's *Marbles: Mania, Depression, Michelangelo, and Me: A Graphic Memoir* and Peter Dunlap-Shohl's *My Degeneration: A Journey Through Parkinson's* as two examples that can serve as pedagogical resources.

Introduction

Graphic medicine, or the use of comics in health care education and patient care, provides patients and clinicians new ways to experience and understand health, illness, and care [1, 2] through visual representations of experiences such as pain, fear, and self-reflection [3, 4]. Usually students are familiar with comics, which make them convenient to introduce as a learning tool [5-7]. The medium lends itself to presentation: pages and single frames from comics are manageable as objects of analysis within a classroom context [1, 3, 4, 8]. Often, what might require complex prose or film is well represented by a single comic frame or page. To depict the complexity of experience, graphic creators often use *emanata*, text or icons that represent thoughts or feelings. Combinations of words and illustrations allow graphic creators to communicate feelings more richly than through visuals or text alone. Comics thus provide students a medium to witness quickly moving thoughts and feelings and also to discern individual action, speech, feelings, and thoughts [1, 3, 9].

Using comics, students can also grasp ethical concepts and problems that are difficult to understand, such as the complex effects of health care on patients' experience of autonomy. In this paper, I advocate using comics to assist teaching about patient experiences related to autonomy because graphic medicine is a medium that uniquely captures dimensions of crisis and deliberation associated with health care.

Using Comics to Teach about Patient Autonomy

Respect for autonomy is a principle of medicine that refers to respect for the patient's ability to self-govern without "controlling interference by others and ... limitations, such as inadequate understanding" [10]. *Relational autonomy* describes the intersubjective and social dimensions of autonomy [11]. Patients experience varying degrees of autonomy within health care contexts that might affect their self-trust and self-evaluation [12]. Moreover, abilities and opportunities to be autonomous are affected by numerous factors, including health literacy, social support systems, inequities, and clinician communication skills [13, 14]. Because turmoil and tension experienced by patients can undermine their abilities to convey their experiences, trainees might be unaware of how patient autonomy is affected by illness, diagnosis, treatment, and clinician communication [15-17]. In what follows, I discuss two examples of graphic medicine that can serve as pedagogical resources for increasing students' understanding of patient autonomy, especially as it relates to diagnosis and treatment.

Marbles. Ellen Forney's graphic memoir Marbles: Mania, Depression, Michelangelo, and Me: A Graphic Memoir is ideal for teaching students about a patient's experience of autonomy following diagnosis and during treatment for bipolar 1 mood disorder [18]. Forney begins with her experience of a manic episode and the therapeutic sessions that follow. She illustrates not only the exchange of dialogue in therapeutic encounters but also the thoughts and images that occur to her during the sessions. For example, she illustrates her second meeting with the psychiatrist, taking the reader through her experience of the symptoms of bipolar 1 mood disorder as listed in the Diagnostic and Statistical Manual of Mental Disorders [19]. This scene familiarizes students with symptom-based medicine as it relates to the patient's experience of self and autonomy. Forney's experience of being diagnosed provides a glimpse into the moment of diagnosis and prompts questions about how it affects her sense of autonomy and agency (see figure 1). Over her torso is a text box, like those in mug shots, stating, "Bipolar I Disorder 296.4" [20]. As she states above the picture that resembles a mug shot, "My own brilliant, unique personality was neatly outlined right there, in that inanimate stack of paper. My *personality* reflected a *disorder—shared* by a group of people" (emphasis added). On one side of her face in the picture is a cloud, below which is written, "This sank in like the sun had gone behind the clouds." On the opposite side and lower is written, "like I'd been covered by a heavy blanket, like a parrot," below which is a draped blanket. Her identity is represented as overtaken by the diagnosis hanging around her neck.



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Figure 1. Graphic novel excerpt from *Marbles: Mania, Depression, Michelangelo, and Me: A Graphic Memoir* by Ellen Forney, copyright © 2012 by Ellen Forney. Used by permission of Gotham Books, an imprint of Penguin Publishing Group, a division of Penguin Random House LLC. All rights reserved.

By using emanata and images that spill over one another, Forney communicates to the reader aspects of mania as she experiences them. When she experiences depressive episodes, Forney uses isolated imagery that communicates her loneliness and hopelessness. Surrounded by her narrative, a single sketch of her maligned body twisted around itself in a bird's nest summarizes feelings of struggle that she could not convey

otherwise. This is evident when she states, "I soon learned to keep drawing until I really nailed my feelings down. I didn't get nearly the same relief if I only came close" [21]. The image conveys her feelings of isolation and helplessness, providing readers with a stark representation of her lack of autonomy caused by depression.

Comics also give Forney the ability to convey how medication threatens her autonomy. The persistent trials with different medications constantly threaten her autonomy: from her ability to control and maintain her desired weight to her self-confidence concerning her treatment decisions. One means by which she attempts to retain her autonomy is by smoking marijuana, despite her therapist's warnings. By withholding her marijuana use from her therapist, Forney struggles to retain a sense of self that is solely her own, apart from relations with others. Readers can witness her thought processes and emotions concerning her diagnosis, her treatment, her sense of identity, and her therapist, who often takes a detached approach to Forney.

In *Marbles*, Forney presents clean, concise, and powerful images, dialogue, and thoughts to portray the complex effects that illness, diagnosis, and treatment had on her autonomy. Comic images like those depicted in *Marbles* can provide common reference points in lectures and discussions to facilitate <u>students' understanding of patients'</u> <u>experience</u> of threats to their autonomy and fears associated with their illness. In *Marbles*, readers can also gain access to the typically private realm of a patient's deliberation, as Forney continually struggles with what to divulge to her therapist and what to retain as solely hers. Graphic narratives such as *Marbles* thus can assist in developing students' caregiving skills and their responsibility to engage with patients' emotional experiences. By depicting her emotional experiences regarding therapy sessions, Forney illuminates the importance of the patient-clinician relationship to her struggle with illness and to her sense of autonomy.

My Degeneration. Peter Dunlap-Shohl's *My Degeneration: A Journey Through Parkinson's* presents another depiction of a patient's experience of autonomy [22]. Dunlap-Shohl is an editorial cartoonist whose abilities, including those required for work, were threatened by Parkinson's. Comics provide Dunlap-Shohl with a means to communicate his experience of illness that other media cannot convey. For instance, he personifies Parkinson's as a man subtly diminishing his ability to self-govern [23] with whom he boxes to regain self-governance [24]. By using motion lines and emanata, he expresses the struggle of contending with the changes Parkinson's and medication brought to his career and sense of self. In a series of illustrations, he depicts the symptoms, such as logorrhea (repetitious and often incoherent speech) and festination (an alteration in gait pattern that is marked by quick and shortened steps), which compel him to act in specific ways that betray his inability to self-govern [25]. He also illustrates his positive experiences with exercise, family, and community, which help students understand autonomy as relational. Through his vibrant characterizations of his experience, Dunlap-

Shohl provides students with a unique view of how his symptoms and social supports relate to his feelings of diminishing and increasing autonomy, respectively.



Figure 2. Dunlap-Shohl, Peter, "The cockeyed optimist," page 8, from *My Degeneration: A Journey Through Parkinson's*, 2015. Copyright © 2015 by The Pennsylvania State University Press. Reprinted by Permission of The Pennsylvania State University Press.



Figure 3. Dunlap-Shohl, Peter, "The gimlet-eyed skeptic," page 8, from *My Degeneration: A Journey Through Parkinson's*, 2015. Copyright © 2015 by The Pennsylvania State University Press. Reprinted by permission of The Pennsylvania State University Press.

Dunlap-Shohl also illustrates his experiences of how physicians diagnose and treat Parkinson's. Included are depictions of how different physicians deliver a diagnosis, such as "the cockeyed optimist" (see figure 2) and "the gimlet-eyed skeptic" (see figure 3), all of whom affect their patients differently [26]. In these figures, Dunlap-Shohl comments on how the delivery of a diagnosis can support or undermine a patient's autonomy and contributes to each patient's experience of illness, and in other frames he suggests what physicians should do to deliver a diagnosis in a way that expresses respect for a patient's autonomy [27]. He also depicts his struggles that were the result of unsympathetic treatment and his successes that were due, in part, to care delivered with empathy and patience. An example of the latter is his experience with a movement disorder specialist on what he refers to as the "Island of the Caring and Competent," which is the world of empathetic people who work with patients to improve the present and future [28]. Through illustration, he communicates the autonomy he achieved through exercise, family support, physicians, peers, and technology. Witnessing these experiences through comic form provides students with a lesson that diagnosis and treatment should be delivered in a manner that acknowledges patients' emotional experiences. Dunlap-Shohl presents his degeneration from Parkinson's as being offset with the autonomy he gains, in part, through his relationships, which include his relationships with his clinicians.

Conclusion

Graphic medicine is useful for explaining patient autonomy to students through media that is amenable to teaching and learning about the diversity and individuality of patient experiences. *Marbles* and *My Degeneration* provide trainees with different experiences of patient autonomy that can increase their ability to understand and express regard for patients whose autonomy and sense of agency can be undermined by illness. Forney elucidates the importance of self-trust and trust between physician and patient and how these two types of trust affect decision making and patient autonomy in the case of a mood disorder. Dunlap-Shohl helps readers understand the importance of diagnosis delivery and its dramatic impact upon a patient's autonomy. By reading and discussing these accounts, trainees can combine principle-based medical ethics training about autonomy with experiential knowledge that aids in diagnostic and critical reasoning in ways that acknowledge patients' emotional experiences. These previously underutilized resources provide trainees with tools to help cultivate their understanding of patient autonomy.

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Mark Tschaepe, PhD, is an assistant professor of philosophy at Prairie View A&M University in Prairie View, Texas, and an adjunct assistant professor at Baylor College of Medicine. He is also a board director for AIDS Foundation Houston, instructor of a course on diversity for the South African Medico-Legal Association, and a consultant for a medical information therapy project at the University of Namibia School of Medicine.

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FROM THE EDITOR

Comics and the Ethics of Representation in Health Care

As a child, I (T.O.) was a voracious consumer of comics. While my parents would dissect out their sections of interest from the Sunday paper, the "funnies" were always set aside and reserved for me. I collected Garfield, Calvin and Hobbes, and Batman comic books, which I would read in my favorite pair of red Dick Tracy pajamas. My mother was an art teacher, so art appreciation and creation were prominently cultivated in my household. For me, the comics I loved were always unquestionably considered a true art form on par with other fine arts. Comics drew me in due to their aesthetic appeal, with their bold colors and expressive characters. What kept me hooked on comics was that these stories allowed for total immersion in the minds and worlds of the characters, offering me a broader experience as a reader than I had with other modes of storytelling.

When I enrolled at Penn State College of Medicine, I was thrilled to discover a course focused on medically themed graphic narratives being offered as a part of the school's medical humanities curriculum. Studying medicine through the lens of comic art felt like a course specifically designed for me. The course was created by Michael J. Green, a physician and bioethicist who helped pioneer the field of graphic medicine. The term "graphic medicine," coined by Ian Williams, a British physician [1], refers to the intersection of comics and health care discourses [2]. Green's class was the first medical school course to teach graphic narratives as a part of medical education, and it opened my eyes to this emerging field.

Many readers might be surprised that comics are being taught in medical school. How can a medium most closely associated with the capers of spandex-clad superheroes possibly address serious topics of health and illness? People are familiar with the historical association of comics with juvenile entertainment or underground movements, but comics are no longer only for children and fringe subcultures. Comics have evolved substantially since the Comics Code was adopted in 1954 [3]. Sparked primarily by the writings of Fredric Wertham, a physician who believed reading comics lead to juvenile delinquency [4], the Comics Code censored comics, setting out rules for permissible content. To be published, comics were required to minimize violence and sex. They were also required to demonstrate respect for authority [1, 2]. These days, comics address every conceivable topic, ranging from the experiences of Holocaust survivors to life growing up during the Iranian Revolution [5-7]. Not surprisingly, comics have also found their way into the medical field through accounts by patients (e.g., *Cancer Made Me a Shallower Person: A Memoir in Comics* [8]), clinicians (e.g., *The Bad Doctor: The Troubled Life*

and Times of Dr. Iwan James [9]), and caregivers (e.g., Tangles: A Story about Alzheimer's, My Mother, and Me [10]).

This issue of the *AMA Journal of Ethics* addresses comics as they apply to medical ethics. It explores a range of issues in using comics in medical education and clinical practice, including as tools for patients and for conveying the experience of illness. Taking a historical perspective, Carol Tilley addresses how the representation of <u>clinicians in</u> <u>comics</u> has changed over time and, in particular, how such portrayals are becoming increasingly realistic. As the comics field diversifies, so does the way clinicians are depicted, a trend that will likely continue to evolve over the next decade.

Three contributions address the role of comics in educating the public. MK Czerwiec writes about social and political activism related to <u>HIV/AIDS</u>, focusing on the role played by comics in health education. Susan M. Squier takes on a related theme, addressing issues of social justice in the <u>development of drugs for the poor</u> in resource-poor countries. In particular, she explores how the educational comic *Parasites!* offers an alternative to the profit motive by emphasizing social and ethical concerns related to drug development in under-resourced countries. In the podcast, Brian Fies and Phoebe Potts discuss their experiences as the authors of graphic novels that deal with health care issues and explain why graphic medicine provides a uniquely powerful medium for <u>communicating about challenging topics</u> in health care.

The concept of graphic pathographies—illness narratives in graphic form [1]—are explored by several authors. Kimberly R. Myers and Michael D.F. Goldenberg show how graphic pathographies have become powerful tools for health care professionals seeking insights into <u>patients' lived experience of illness</u> and the benefits of these depictions for health professions students and patients alike. Mark Tschaepe shows in particular how graphic narratives can illuminate <u>patients' experiences of autonomy</u>. Using a specific example of graphic pathography focused on a teen with mental illness, *Swallow Me Whole*, Jared Gardner argues that the reader's participation in making meaning provides a model for collaboration among patients, clinicians, and caregivers. Linda S. Raphael and Madden Rowell explore the representation of those with illness or disability, arguing that examining patients' and clinicians' <u>subjective experience of care</u> underscores the importance of treating patients with dignity, compassion, and respect.

In recent years, comics have been incorporated into formal medical school curricula around the world. Using an original comic created by Mónica Lalanda, Lalanda, along with Rogelio Altisent and Maria Teresa Delgado-Marroquín, describe how a written code of ethics was transformed into an effective <u>comic to teach medical students</u>. Jeffrey Monk focuses on the topic of <u>abusive treatment of medical students</u> using a comic he created when enrolled in a graphic medicine course as a medical student. He contends that comics can be a safe space for expression and for sharing experience and hence are an

effective medium for addressing this sensitive issue. Megan Yu discusses the skills and attitudes that medical students can learn from reading and creating comics as well as the ethical challenges of using <u>student-generated comics</u> in teaching.

Comics are not only being used to educate medical students but also as effective patient education tools. Gary Ashwal and Alex Thomas discuss the appropriateness of comics as <u>patient educational materials</u>, arguing for the importance of ensuring accuracy of information, respecting patients' preferences for educational format, and presenting comics in a sensitive manner.

Comics can no longer be dismissed as "low-brow" and unworthy of scholarly exploration. They have become part of the educational environment and can provide meaningful commentary about the social, cultural, and ethical landscape where patients, caregivers, clinicians, and learners intersect. It is our obligation to critically evaluate these works and address some of the uncomfortable questions they raise. This issue of *AMA Journal of Ethics* on comics in medicine aims to increase awareness of and further legitimate these works while beginning to address head-on some of the ethical issues surrounding their use.

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Taylor Olmsted, MD

PGY-6

Department of Pediatric Hematology-Oncology Texas Children's Hospital and Baylor College of Medicine Houston, Texas

Michael J. Green, MD, MS

Interim Chair, Department of Humanities Director of the Program in Bioethics Penn State College of Medicine Hershey, Pennsylvania

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ETHICS CASE

Are Comic Books Appropriate Health Education Formats to Offer Adult Patients?

Commentary by Gary Ashwal, MA, and Alex Thomas, MD

Abstract

Physicians who recommend patient education comics should consider that some patients might question the appropriateness of this format, especially in the US, where a dominant cultural view of comics is that they are juvenile and intended to be funny. In this case, Dr. S might have approached communication with Mrs. T differently, even without knowing her attitude toward comics as a format for delivering health information. Dr. S could acknowledge that though some people might not expect useful medical information in a comic format, it has unique aspects and new research on patient education comics shows that even adults are finding this medium to be effective, educational, and engaging. Offering comics to patients, however, does potentially require patient educators to invest additional time to review and assess their accuracy and relevance.

Case

Dr. S is a psychiatrist who is seeing Mrs. T, a 45-year-old woman, in his clinic. She was referred for difficulty sleeping and anxiety following a massive car accident two months ago. Mrs. T also has been having panic attacks and is now afraid to drive on the highway. After telling her story to Dr. S, she asks for his opinion. Dr. S explains he believes she is experiencing posttraumatic stress. He further explains that there is a diagnosis called posttraumatic stress disorder (PTSD); he suggests some interventions for helping her manage her symptoms.

On her way out of the exam room, Dr. S pulls a booklet from a display on the wall. Dr. S is aware of the growing literature that supports comics as an effective patient education tool and has stocked several educational comics in his office on a variety of psychiatric disorders. Patients have told him that this booklet in particular resonated with them in describing what it is like to suffer posttraumatic stress.

"Here," he says, handing her the booklet. "Some patients find this helpful." Mrs. T looks down at a comic book titled "Trauma and You." She is surprised to see posttraumatic stress represented in comic form. Not wanting to be rude, she just thanks him and quietly leaves the clinic. Walking out of the clinic, she hurriedly flips through the pages. Using cartoon images and text, the book details a man's experience with PTSD. Mrs. T stops and calls her husband. "I can't believe he gave me a comic book!? The accident isn't funny, it's serious! What is Dr. S thinking!?" She throws the comic in the garbage outside the clinic door and begins to walk home. She wonders, "Does Dr. S think I'm stupid or something? Why does he think I need a children's book? Why would he think I'd find this helpful?" Mrs. T did not return to Dr. S for further care.

Commentary

The American Medical Association *Code of Medical Ethics* states that physicians should "present relevant information accurately and sensitively, in keeping with the patient's preferences for receiving medical information" [1]. As such, it is important for Dr. S to ask himself these questions: (1) Does the comic book given to Mrs. T convey relevant, accurate health information? (2) Have Mrs. T's views about the appropriateness of comics and her broader preferences about how to receive information been solicited by Dr. S? (3) If Mrs. T's views comics as inappropriate or does not want to see health information conveyed this way, how should Dr. S respond?

In the following commentary, we will address the above questions by considering the similarities and differences between comics and other types of patient education materials and by examining the formal aspects of comics that could be beneficial for patient education within two categories of health-focused comics. Additionally, we will suggest possible strategies for presenting comics to patients who might be unfamiliar with this type of format in patient education materials.

Comics versus Other Patient Education Formats

To provide relevant and accurate information, clinicians can choose to give or recommend to patients additional educational materials to supplement any verbal medical information they communicate during an appointment. These materials can be in the form of handouts, videos, websites, comics, or other media types. All formats have potential to contain relevant and accurate information. Similarly, any format can also be poorly written, out-of-date, medically inaccurate, or irrelevant.

Comics are similar to other patient education formats in that clinicians should consider their own confidence in the content. Even clinicians who choose to use comics might have additional concerns, including how adult patients might react to receiving a comic about a serious medical topic. In contrast to Mrs. T's opinion of comic books as "funny," examples of comic books addressing serious health topics abound: *Marbles: Mania, Depression, Michelangelo, and Me: A Graphic Memoir* [2], *The White Donkey: Terminal Lance* [3], *Taking Turns: Stories from HIV/AIDS Care Unit 371* [4], and so on. Nevertheless, most adult patients in the US are unlikely to have received a comic book from a doctor and might need to be reassured that comics can indeed communicate relevant and accurate information. Furthermore, a clinician in Dr. S's position might also want to explain why he or she recommends a specific comic for a specific patient. This explanation might differ depending on the type of health-focused comic offered to the patient.

Types of Health-Focused Comics

In recent years, a growing body of research has demonstrated the potential effectiveness of <u>comics as a patient education tool</u> [5-7]. Broadly, there are two categories of health-focused comics that appear in this graphic medicine literature: (1) memoirs about a personal health, medical, or illness experience; and (2) instructional content designed to educate patients. This case does not specify the precise category to which *Trauma and You* belongs—and it could possibly combine features of both categories. Accordingly, this section will discuss both categories as well as unique aspects of comics that enable the format to provide accurate and relevant health information.

Personal memoir comics. The first category—personal memoir comics—is sometimes called graphic pathography and is often created by an individual writer-illustrator who tells the story of his or her own health care experience. These comics can range from a realistic, documentary-like style (e.g., *Mom's Cancer* [8] and *Our Cancer Year* [9]) to more metaphorical representations (e.g., *Spot 12: Five Months in the Neonatal ICU* [10] and *Hyperbole and a Half: Unfortunate Situations, Flawed Coping Mechanisms, Mayhem, and Other Things That Happened* [11]). By definition, this genre of comics focuses on the experience of a particular person, which might factually differ from that of other patients or caregivers. Therefore, clinicians should keep in mind that the value for patient education may be more in the author's depictions of relevant concepts and accurate representations of potentially relevant emotions than in the author's communicating detailed and comprehensive medical information.

Suppose that the comic book *Trauma and You* that Dr. S hands to Mrs. T is a personal memoir. If this is the case, Dr. S should first be confident that its content might be something Mrs. T would find relevant to her own situation. For example, what if the comic book was about experiences of someone with PTSD after a military trauma, not a car accident? To bridge this difference, Dr. S could explain to Mrs. T how the experiences, symptoms, and treatment of PTSD can be similar even when stemming from two very different traumas. Additionally, comics are notable for their ability to invite a broad spectrum of readers to identify with unique characters, because the visual representation of characters can be more abstract and symbolic than photorealistic representations [12]. As such, comics have the power to invite the reader to relate to the characters more easily, which could allow Mrs. T to relate to a comic book character whose experience does not align exactly with her own experience of PTSD. Dr. S could

even point out this idea to Mrs. T as a possible reason why his other patients had found the comic helpful.

Health education comics. The second category—health educational comics—is more like the type of patient education format that straightforwardly explains medical information. However, instructional comics are very different from handouts that use bullet-point lists or brochures that use photographs. Comics have a unique grammar that McCloud defines as "juxtaposed pictorial and other images in a deliberate sequence, intended to convey information and/or to produce an aesthetic response in the viewer" [13]. Comics have been used to communicate accurate and relevant information on serious and technical topics over many decades and across cultures [14]. Instructional comics can use narrative (e.g., "Sophie's Science Project: What Is Medical Research?" [15] and *Forgotten Memories* [16]) or be more didactic (e.g., *Trauma Is Really Strange* [17] and "Let Me Tell You How Dad Got Sick!" [18]).

The grammar of comics might be able to facilitate comprehension to a greater degree than other patient education formats. One well-known feature of comics is the carefully designed interplay of words and pictures, which can help improve health literacy. For example, sequences of action can be depicted visually that might otherwise take many paragraphs of written text to explain in equivalent detail, and the sequence itself could contain concise speech bubbles or captions that complement or clarify the visual information. In addition, spatial relationships between illustrations can create a dynamic depiction of time, which could be used to help explain cause-and-effect information related to certain medications or health behaviors. Another graphic technique of comics is the juxtaposition of differing images on the page. This technique can be useful to contrast healthy and unhealthy or disease states (e.g., normal vs. asthmatic airways) or to compare observable external symptoms and internal physiological processes (e.g., wheezing vs. bronchoconstriction) [19]. Taken together, these features give comic readers a multilayered experience, encouraging repeated reading that could continue to reinforce educational concepts well after the patient visit. If *Trauma and You* is a health educational comic book, Dr. S could point out to Mrs. T why he feels this unique format presents this medical topic more clearly than other materials he has reviewed.

Presenting Patients with Comics

In the case, Mrs. T believes that comics are only for children and that the medium is not an appropriate format for serious subject matter. Physicians who recommend patient education comics should address possible patient attitudes questioning the appropriateness of this format, especially in the US where the dominant cultural view of comics is that they are juvenile and intended to be funny.

It is important that Dr. S present this information sensitively, in keeping with Mrs. T's preferences. It is not clear if Dr. S specifically solicited Mrs. T's broader preferences about

receiving medical information or her specific feelings about comic books. However, Dr. S might have approached <u>communication</u> with Mrs. T more sensitively, even without knowing her personal preferences for patient education format.

Dr. S could have acknowledged that some people might not expect useful medical information to be presented in a comic format. He might have also chosen to mention that new research published in medical and health journals demonstrates this medium to be an effective and engaging educational tool for both children and adults [5-7]. In providing context that comics can address serious topics, he could have referenced famous comics that have become mainstream hits, even if these are not specifically health related, such as *Maus: A Survivor's Tale* [20], *Persepolis* [21], and *Fun Home: A Family Tragicomic* [22]. To better assure Mrs. T of the relevance of the comic to her medical issues, Dr. S could have pointed out a few specific details about how and why he feels this specific comic book, story, or character might relate to her. Most importantly, Dr. S might have affirmed to Mrs. T that many comics he offers to patients meet the same standards (e.g., accuracy, readability, up-to-date information) of other patient education content in other media formats that might be more familiar to her.

If Mrs. T indicates that she views comics as inappropriate, and if additional information does not persuade her, Dr. S could potentially choose to offer her the comic book anyway but also convey that she need not read it. If Dr. S adamantly feels this particular comic is the best version of PTSD patient education he can provide, it might be worth taking the chance that Mrs. T is simply expressing a negative viewpoint because she feels it would be inappropriate for her to accept the comic but that she might potentially still read it later. At the same time, Dr. S could also accommodate Mrs. T's stated preferences for more serious-appearing information and refer her to reputable websites or other materials that he might have available.

Conclusion

When determining the appropriateness of a health-focused comic for adult patients, clinicians may need to invest more time than they do with other formats. For example, they might have to do their own evaluation of the accuracy of the content, because comics are less likely to be included in a standardized collection of physician-reviewed patient education materials that practices or hospitals might already use. Similarly, they might need to review each comic for its potential relevance to their own patients in terms of the artwork style, storytelling approach, and emotional content. Finally, clinicians need to be prepared to present this less-common format in a sensitive manner by explaining its potential educational advantages and particular usefulness. In this effort, clinicians do have a growing number of resources, including medical librarians, websites, and journals that are beginning to evaluate and organize graphic medicine titles in a way that could make it easier for clinicians to know which comics to recommend to patients [23, 24].

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Gary Ashwal, MA, is a health communication specialist and multimedia content producer based in Los Angeles and the co-founder of Booster Shot Media. He earned a master's degree in health communication from Emerson College and Tufts University School of Medicine and a BS in performance studies from Northwestern University.

Alex Thomas, MD, is a pediatric allergist and immunologist based in Chicago and a cofounder of Booster Shot Media. In addition to his clinical practice, he is also a cartoonist and illustrator with more than 20 years' experience. He earned a BA in art theory and practice from Northwestern University and an MD from Rush Medical College and completed both his pediatrics residency and his allergy/immunology fellowship at the University of Wisconsin School of Medicine and Public Health.

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ETHICS CASE

Go Home, Med Student: Comics as Visual Media for Students' Traumatic Medical Education Experiences

Commentary by Jeffrey Monk, MD

Abstract

A comic created by a medical student allows the reader to share the student's own unique perception of the medical education experience. Through the process of comic creation, medical students have opportunities to gain insight into how their relationships with patients and supervising physicians have shaped the physician they will become. The comic itself can be a safe space for expression and provides an opportunity for students and educators to share experiences.

Case

Dr. Charles, who has a busy schedule in clinic today, is seeing his long-time patient Mrs. Chapman. Mrs. Chapman has come in several times in the past for concerns about leftsided chest pain. He had previously attributed her complaints to anxiety.

As depicted in the comic below, created and illustrated by the author when he was a fourth-year medical student, Dr. Charles flippantly dismisses Mrs. Chapman's concerns. A third-year medical student who is shadowing Dr. Charles attempts to question his quick judgment. This inquiry is met with harsh belittling of the medical student. The student is shocked by this reproach but abandons his line of questioning into the management of Mrs. Chapman's chest pain.



Figure 1. Excerpt from "A Ghost of an Idea," by Jeffrey Monk. © Jeffrey Monk. Reprinted by permission of Jeffrey Monk.

Commentary

As a fourth-year medical student, I was fortunate enough to participate in the graphic medicine humanities elective offered by Michael Green at Penn State College of Medicine. This course was designed to use graphic texts to enrich the medical education experience. The medical students read and discussed multiple "graphic pathographies," comics intended to share authors' own experience with disease, or perhaps the illness of a loved one, and their journey navigating the health care system [1]. Books such as *Stitches: A Memoir* [2], *Tangles: A Story about Alzheimer's, My Mother, and Me* [3], and *Swallow Me Whole* [4] allowed the students to reflect critically on topics such as empathy for patients and how sickness affects the experiences of patients and their families. Green and illustrator Ray Rieck also instructed students on the practical aspects of comic creation. Green's own example of graphic medicine, "Missed It," was used as a case study for how physicians can use comics as a tool to reflect on their own experiences during medical training and pass on valuable lessons to others in the medical profession [5]. By the end of the course, the students had studied the methods of comic creation, analyzed graphic medicine comics created by both patients and physicians, and applied

that knowledge to create a comic informed by their own experiences with disease and the health care system.

In the following sections, the comic I created will be used as a case study to explore how graphic medicine can be used to represent a medical student's perception of an interaction between his mentor clinician and a patient. In particular, the comic will be used to discuss ethical issues of the <u>medical hierarchy</u> and the place of medical students therein, as well as the potential loss of identity that may be experienced by students during medical school. Finally, the benefits of including medical students in the process of creating graphic pathographies will be discussed.

Origins of "Ghost of an Idea"

Panels A through E of figure 1 are excerpted from the comic, "A Ghost of an Idea," which I wrote and drew for Green's course [6]. The comic follows a storyline that mirrors Charles Dickens's "A Christmas Carol," with Dr. Charles playing the role of Ebenezer Scrooge. Dr. Charles is not a real person, but his dismissive behavior and poor conduct are based upon real people. I interacted with one physician in particular during my medical school years who, unknowingly, served as a valuable example of how not to listen to the patient and how not to appropriately address the patient's concerns.

Using the Comics Medium to Show and Tell the Reader

Dr. Charles feels comfortable in his role as The Attending Physician: he has accrued decades of experience as a physician and thus appears to feel his opinions must be infallible. We see in figure 1, panel A, how he makes the mistake of diagnosing his patient before even stepping into her room. He feels so sure he can deduce, based on past experiences, exactly what is ailing Mrs. Chapman that he intentionally foregoes any mote of proper history-taking or physical examination. The unnamed medical student is forced to sit by idly, absorbing this exchange between physician and patient. The word balloons in figure 1, panel B, visually represent the conversation overheard by the medical student: as Dr. Charles cuts off Mrs. Chapman's plea for understanding, so, too, does the speech bubble issuing forth from Dr. Charles's mouth overshadow the small, abruptly silenced word balloon originating from Mrs. Chapman. The medical student continues to observe this interaction. The perspective shifts in panel C of figure 1 to the dismayed look of disappointment in a close-up shot of Mrs. Chapman's face. There is no text in this panel, only the image of her face, possibly seen through the eyes of the medical student witnessing the results of Dr. Charles's behavior: her concern was not heard. In addition to her reason for coming to the office being dismissed, she was belittled by Dr. Charles, who complained to the medical student about her "frequent flyer" status as a patient in his office.

The art in these first three panels lets me show my perspective of this event: I was the fly-on-the-wall medical student, shadowing my supervisor but absorbing the details of

the interaction between physician and patient. Representing this type of patient interaction graphically affords learners an opportunity to witness patient maltreatment in a safe, ethical manner in which no patient is actually harmed.

Analysis of the Case

To analyze the case, I will use Green et al's article, "The Comics Revealing Medical School's Hidden Flaws and Hard Lessons," which identified the themes that have been most often present in the comics written and illustrated by medical students [7]. Two themes the authors identified are on display in the panels shown in figure 1 and discussed below.

Medical hierarchy. First, the hierarchy of medicine generally places the attending physician squarely at the top and the medical student firmly at the bottom. This is not a topic that is covered during medical school orientation, yet each medical student, particularly during third-year clinical rotations, quickly learns his or her place within this assumed hierarchy. A primary objective for the medical student is to listen and learn from those members of the medical team perched on the higher rungs of the medicine ladder, even if their behavior contravenes what is explicitly taught in the curriculum. Behaviors are one part of the hidden curriculum of medical school: the cultural milieu encompassing the student as he becomes integrated into the health care team [8]. The medical student in this case should strive to apply the concepts he has already learned and question the reasoning and decision making of his superiors. Decisions about diagnosis and treatment should be evidence based, morally and ethically sound, free of bias, and respectful of patient autonomy.

Panels D and E of figure 1 demonstrate this role of the medical student. The medical student recognizes that Dr. Charles has not followed the standard of care by taking a proper history and physically examining Mrs. Chapman before proclaiming his diagnosis. The student attempts calling this misstep into question, but in panel E he is quickly reprimanded by Dr. Charles, who first confirms the student's status: yes, he is a third-year medical student, so he is at the very nadir of the medical hierarchy. Dr. Charles not only dismisses the student's question, but also physically dismisses the student to prevent any further inquiry into his own authority and experience.

Loss of identity. Another theme identified by Green et al. [7] and represented in the comic concerns the loss of identity and individualism that can occur during medical school. In addition to the example provided by my comic, other comics created by medical students for Green's course feature the generic appellation "med student." From the student authors' point of view, the use of this term is intended to show how students are deidentified and interchangeable in the eyes of their superiors. Dr. Charles probably does not know the medical student's name, and, as far as he is concerned, he probably does not need to. As seen in panels B and E of figure 1, Dr. Charles only refers to his mentee

as "med student." The young man who was likely assigned to work with and learn from Dr. Charles is just another anonymous med student to him. When Dr. Charles sends away his learner, he proclaims, "Go home, med student." The scene ends there, with a look of shock and awe on the medical student's face as he accepts this rebuke from his supposed mentor. The immediate consequence of Dr. Charles's harsh treatment of the medical student in panel E of figure 1 is left in the gutters: the empty space between comic panels where the reader fills in the missing details.

A student in that situation is more than likely going to be less forthcoming with questions for the remainder of his clinical rotation. Some students might experience anxiety related to even working, speaking, or listening to an attending physician like Dr. Charles, and their educational experience could suffer as a result. For example, a national survey of third-year medical students conducted in 2011 found that the majority of respondents reported at least one incident of mistreatment by faculty or residents since they began their clinical rotations [9]. A smaller subset of students also reported recurrent mistreatment by faculty or residents, and these students were more likely to have higher burnout than students who reported no or infrequent mistreatment [9]. Although the survey did not define or give examples of "mistreatment," mistreatment could be defined in a variety of ways, including racial or gender discrimination, physical intimidation, or humiliation or belittlement (as in the case presented in figure 1).

The Benefits of Incorporating Graphic Medicine into Medical Education

The students in Michael Green's humanities course at Penn State College of Medicine including me—benefited greatly by going through the process of creating a comic from start to finish. The process involved first brainstorming ideas for the comic, which allowed each student to reflect on his or her medical experiences thus far not only as a medical student but also as a patient or family member of someone who had a meaningful encounter with the medical system. The graphic pathographies read and analyzed for the course served as vital guides for how to approach this introspection. What were the difficulties encountered while navigating the health care system? How did it feel to participate in patient care, to heal and to serve others? How did it feel to witness loss due to disease or a medical error? The students discussed their ideas for comic concepts, which encouraged dialogue regarding what experiences, whether positive or negative, they felt were valuable components of their medical education. Experiences like those illustrated and discussed above were shared and analyzed among the group of students.

A topic that would have been awkward or intimidating to discuss with the attending faculty during a clinical rotation could be safely presented for others to explore through the student-created comic. For most students, the comic art is crude; after all, it is a medical school course, not art school, but the simplified art can help preserve the anonymity of the people presented in the comics. I was able to present Dr. Charles as a

generic, middle-age male attending physician and the medical student as an equally generic young male. These comic characters represent real people to me, but anyone else can read and view the comic and understand the relationship between the characters without any blame or scorn being directed at a specific individual. This expressive characteristic is not unique to the comics medium, of course. Students can also compose written stories to express their experiences during medical school, but in that case the story is ultimately left up to the reader's interpretation of it. Comics are different. The burden lies with the artist to visually tell the story, but the combination of pictures and words is complete and will show the reader exactly the story the author intends.

Conclusion

Using comics in medical education serves a dual function. It is a safe method of expression for a medical student. In this case, it was a way for me to convey my interpretation of the poor patient care I witnessed and my frustration with the way I was mistreated by a mentor. Comics also serve as an educational tool. The comic presented here can be used to show other students an example of a negative physician-patient interaction and encourage students to discuss other ways Dr. Charles could have handled the situation with a more patient-centered approach. The representation of the medical student in the comic could also serve as a starting point for discussion by students regarding their own mistreatment during their medical training. Comics are a powerful educational tool, and it is my hope that many more classes of fourth-year medical students at Penn State College of Medicine—and hopefully students at many more medical campuses—get the opportunity to read, discuss, and create graphic pathographies.

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Jeffrey Monk, MD, is a general pediatrician practicing in York, Pennsylvania. He attended Penn State College of Medicine and remained in Hershey, Pennsylvania, for his pediatrics residency at the Milton S. Hershey Medical Center Children's Hospital. He is a life-long fan of comics and graphic novels, and keeps a hoard of comic books in long-boxes under his bed because he may want to read them again someday.

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ETHICS CASE

How Should a Stigmatized Diagnosis Be Conveyed? How What Went Wrong Is Represented in *Swallow Me Whole*

Commentary by Jared Gardner, PhD

Abstract

This essay considers the ethical problems raised by a scene of diagnosis presentation in Nate Powell's graphic novel *Swallow Me Whole*, in which the patient is not only not engaged by the physician, but also effectively marginalized from the moment that her condition is named and medicalized. Put in the context of the book as a whole and in relationship to the unique affordances of the comics form, however, we see that though the physician made a correct diagnosis, the case did not end well due to the poor delivery of that diagnosis and the lack of support from members of the patient's extended community.

Case

Ruth, a teenager with a family history of schizophrenia, has been seeing visions of insects. She has difficulty discerning reality from hallucinations, and her resulting inattention has been noticed by her parents. As depicted in the comic below, Ruth goes to see a psychiatrist who gives her the diagnosis of schizophrenia. The physician rambles about Ruth's symptoms and the incidence of schizophrenia and finally provides a prescription, presumably for antipsychotics. Ruth does not engage in any discourse with her physician and ultimately disappears from the comic.


Figure 1. Excerpt from *Swallow Me Whole*, by Nate Powell. © 2008 Nate Powell. Reprinted by permission of Top Shelf Productions.

Commentary

In the narrative case studies by which we judge the efficacy and ethicality of a clinical encounter, we often see staged clearly marked successes or failures—"good doc" versus "bad doc." However, graphic narrative as a form of storytelling is not always well suited to such didactic lessons. One of its paradoxes is that, on the one hand, it relies on highly

compressed and distilled language and images that create the illusion of transparency, while, on the other, it is so elliptical and marked by gaps that it opens up ambiguities that can only be resolved by the active engagement of the reader. All of this makes graphic narrative not only a challenging source of clinical case studies but also a potentially rich one.

Looking at this case we see evidence of a flawed scene of diagnosis in that the psychiatrist addresses himself to the mother, seemingly erasing the teenaged patient, Ruth, from her own care. However, we have every reason to believe the diagnosis and the prescribed treatment are appropriate. Further complicating our ethical engagement with this page, as we will see, is the fact that the narrative's telling is interwoven with another scene involving Ruth's stepbrother, Perry, whose own scene of diagnosis will further problematize attempts to draw from the text clear ethical judgments.

Swallow Me Whole [1] presents a case study by which to consider a scene of diagnosis that is at one and the same time a success and a failure. Here Ruth is being diagnosed by Dr. Newell following an oral history from the mother and a series of tests with Ruth herself. As readers who have had privileged subjective access to Ruth's view of reality throughout the book, we have little reason to question the accuracy of the diagnosis of <u>schizophrenia</u>. Ruth has indeed been disassociating with increasing frequency, and her visions—dominated by swarms of cicadas invading interior spaces—have been getting stronger and more elaborate. We have seen, as well, evidence of her growing inability to communicate with family and peers. The diagnosis itself seems a reasonable one.

Nonetheless, we are encouraged to question the way in which the diagnosis is delivered. To begin with, Dr. Newell addresses his comments to the mother, despite the fact that Ruth is positioned appropriately in front of his desk. As he speaks of Ruth's condition in the third person, we see a graphic representation of Ruth beginning once again to disassociate—first as the office dissolves behind her in a field of white and then as she herself dissolves into negative space while the clutter of ambient noise alone preserves the outline of her physical being. No evidence of eye contact with Ruth is visible on the page.

From this page alone, one might assume that Ruth has been completely noncommunicative, thus potentially justifying the behavior of the doctor. However, readers of the graphic novel will have seen Ruth regularly engage with adults even as the severity of her condition worsens, and she cooperated with Dr. Newell's "performance tests," answering all questions asked of her. There is in truth no explanation for the doctor's failure to engage with the patient save that, in having made up his mind as to her condition, he has already written her off as an agent in her own recovery, turning all of his attention instead to the mother. The scene of naming—"some schizophrenic and dissociative patterns"—thus also becomes a scene of erasure.

It is also important to note that, even as the diagnosis continues to be delivered uninterrupted in the text of the page, three of the seven panels visually narrate a different space entirely, with actions playing out at the same time involving the second of the book's protagonists, Ruth's stepbrother Perry. We encounter Perry here after he has just escaped from a violent encounter with a school bully, only to now find himself challenged by a security guard. Like Ruth, Perry has experienced visions—in his case, of a small wizard who compels him to draw. When, a few pages later, Perry brings his concerns about his visions to his doctor, however, the scene plays out very differently than it had for Ruth. Here, the father is asked to leave and the physician, Dr. Connoly, addresses Perry directly, asking questions and making eye contact throughout. When Perry explains the compulsions brought on by his wizard, the doctor asks to see the drawings themselves and praises them. All of this seems to point towards the kind of effective and humanizing clinical interview we recognize as preferable to that performed by Dr. Newell.

In the end, however, the diagnostic encounter is not satisfactory for Perry. Dr. Connoly does take Perry's art seriously, but he is dismissive of the concerns that brought him to the office in the first place, lightly suggesting that Perry himself is "clearly a wizard" and that "a few problems are always normal." Dr. Newell had ceased to see Ruth as a human agent the minute he made up his mind regarding her diagnosis; conversely, Dr. Connoly's confidence in Perry's agency and the evidence of his artistic talent makes him unable to take seriously Perry's concerns that he might be suffering from mental illness.

One last thing worth pointing out on the page of our case study: the "parallel editing" (to borrow film terminology)—by which we see Perry's conflict with the bully interwoven with the narration of Ruth's diagnosis—is not typical of Powell's narrative approach elsewhere in the book. This is in fact the most extended example of such narration across two (presumably) simultaneously-occurring events in two (clearly) different spaces, extending over the full four pages from Ruth's first meeting with Dr. Newell to the end of the page we have before us. When Perry is diagnosed (or fails to be diagnosed) a few pages later, there is no similar parallel editing, and the scene itself is laid out in a conventional nine-panel comics page grid. So why does Powell tell the story of Ruth's diagnosis in a way that imbricates it from beginning to end with Perry's fight with the bully (who originally targeted the siblings following one of Ruth's first public psychotic episodes)?

I would argue that Powell wishes us to recognize the degree to which Ruth's understanding of her illness is inextricable from her relationship with her stepbrother. As the biographical note to the book tells us, Powell worked with adults with developmental disabilities [1], and from that experience he knows well that no illness is ever just between doctor and patient. The collaborative nature of graphic narrative discussed earlier—in which readers must actively participate in the process of meaning making makes the form well-suited to modeling "networked" narrative medicine—an approach to <u>caring for a patient</u> that extends beyond the patient-physicians relationship to include family, teachers, employers, authority figures (like the security guard), and so on. And, in these terms, we might understand that while Dr. Newell's failure to address Ruth during her diagnosis is far from ideal, his inclusion of the mother in the scene of the diagnosis is appropriate both because of Ruth's status as a minor and because the illness itself will require active collaboration and education on the part of family, teachers, employers, and so on. When things go wrong for Ruth at the book's end, it is because parents, teachers, and employers failed in their responsibilities as informed caretakers, *not* because of Dr. Newell's delivery of the diagnosis.

The fact that we see the events befalling Perry—his encounter with a bully and a security guard—simultaneously with Ruth's diagnosis, in fact, could be read as suggesting the ways in which their conditions are interwoven in ways Ruth recognizes but her family will not. In these terms, it is worth noting that while Dr. Newell erases Ruth by focusing all of his responses entirely on the mother, Dr. Connoly pushes the father out of the room and focuses all of his attention on Perry in isolation. In the end, neither of these extremes proves effective. A differently staged diagnosis would not necessarily have led to a better outcome for Ruth, as long as parents, teachers, employers, and classmates misread and misjudged her behavior and silenced her more effectively than Dr. Newell ever could. In the end, Dr. Newell might well have been right (even if for entirely wrong reasons) to focus his energies on the mother as opposed to Ruth, given that the adults in Ruth's life needed the education more urgently than she did. Unfortunately, the lessons did not take, and Ruth ends up erased once and for all from her own experience.

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Jared Gardner, PhD, is professor of English at The Ohio State University in Columbus, Ohio. He is the author of three monographs, including *Projections: Comics and the History of 21st-Century Storytelling* (Stanford University Press, 2012), and he is editor of *Inks: The Journal of the Comics Studies Society.* He is currently working on a book, tentatively titled *Patient Time*, about graphic narrative, time, and illness.

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MEDICAL EDUCATION

Teaching Confidentiality through Comics at One Spanish Medical School

Artwork by Mónica Lalanda, MD, MSc, and caption by Mónica Lalanda, MD, MSc, Rogelio Altisent, MD, PhD, and Maria Teresa Delgado-Marroquín, MD, PhD

Abstract

At the University of Zaragoza in Spain we developed an innovative way to teach the concept of confidentiality to medical students, which we tested by comparing the use of customized comics with more traditional methods. We proved that using comics is more attractive to students than lectures and class discussions, that it increases class participation and students' self-awareness of learning, and that it maintains the same academic results. We share our experience visually in a two-page comic.

Comics For Medical Students: A Spanish Experience





Figure 1. *Comics for Medical Education: A Spanish Experience*, by Mónica Lalanda, Rogelio Altisent, and Maria Teresa Delgado-Marroquín

Caption

Comics are increasingly used in medical schools as a tool for students to reflect on their own experience, increase their empathy towards patients, and improve their communication skills [1]. However, as far as we are aware, using customized comics to teach students specific content in health care ethics has not been attempted anywhere before. At the University of Zaragoza in Spain, we developed an innovative educational project: we created comics about confidentiality specifically for medical students and used them to teach preclinical students as part of their compulsory training. We're now so convinced that comics should be used to teach even the most ethically complex concepts that we use a comic format to explain our experience to you as readers.

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Mónica Lalanda, MD, MSc, is an emergency medicine physician in Spain and holds master of science degrees in medical ethics and bioethics. She is also a comic artist.

Rogelio Altisent, MD, PhD, is a general practitioner with the Research Group in Bioethics at the University of Zaragoza in Aragón, Spain. His professional interests include family medicine, bioethics, professionalism, education, teaching innovations, and clinical ethics committees.

Maria Teresa Delgado-Marroquín, MD, PhD, is an assistant professor of ethics at the University of Zaragoza Medical School in Aragón, Spain, where she also practices at Delicias Norte Health Center. She is trained as a bioethicist and general practitioner.

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MEDICAL EDUCATION

Graphic Pathographies and the Ethical Practice of Person-Centered Medicine

Kimberly R. Myers, MA, PhD, and Michael D. F. Goldenberg, MA

Abstract

Graphic medicine is a swiftly growing movement that explores, theoretically and practically, the use of comics in medical education and patient care. At the heart of graphic medicine are graphic pathographies, stories of illness conveyed in comic form. These stories are helpful tools for health care professionals who seek new insight into the personal, lived experience of illness and for patients who want to learn more about their disease from others who have actually experienced it. Featuring excerpts from five graphic pathographies, this essay illustrates how the medium can be used to educate patients and enhance empathy in health care professionals, particularly with regard to informed consent and endof-life issues.

Introduction

Over the past eight years, <u>graphic pathographies</u> have become powerful tools in medical education and patient care [1, 2]. From these stories, practitioners and trainees can discover details they might not have known or fully understood about how an illness can impact a person's daily living. Similarly, patients can learn new information from others who contend with the same illness. These new perspectives can help lessen the isolation that patients often feel and can also help patients cultivate practical skills that might enhance their <u>autonomy</u> and moral agency. This essay provides a brief overview of the advantages of the comic medium as well as a practical method for teaching graphic pathographies, with special attention to empathy, informed consent, and end-of-life decision making.

The Importance of Story

Two key goals of medical practice are competence and compassion. In order to be competent, one must understand illness in all its complexity—that is, both its pathophysiology and its impact on the patient on a social and emotional level. Physicians must come to know and comprehend a patient's story, perhaps especially how the patient experiences illness when she is not in the doctor's office. An awareness of this lived experience of illness helps physicians help their patients to manage disease and its sequelae. Information learned through stories is more likely to be retained [3]; this is perhaps a chief reason that medical education features case-based learning. When we

both hear and *see* stories unfold, perhaps we remember things even more vividly hence the presence of real patients who tell their stories to medical students [3] and the ability of seasoned medical practitioners to remember "one patient, Mr. Z, twenty years ago," who presented with unusual symptoms. Graphic pathographies are thus an excellent means to retain information and hone the interpretive abilities necessary to treat the whole patient.

Advantages of Comics

As a medium, comics have several benefits for trainees and patients [1, 2]. From the outset, comics can seem inviting because of their association with pleasure reading and lightheartedness. Moreover, the medium seems inherently accessible: there's little expectation that one must interpret a comic in a certain way. As cartoonist Chris Ware says, "You don't blame yourself for not 'getting' a comic strip—you usually blame the cartoonist" [4]. This psychological advantage can be particularly important to medical students who are inundated with heavy reading and continually under pressure to get things right on exams and in their new duties on the wards. For a patient or family member who wants to learn about a disease, comics can be disarming—an inviting, nonthreatening way to familiarize oneself with a condition that is perhaps itself inherently threatening.

The comics form also has several advantages over words or images alone. Because words and images complement each other in comics, neither has to do the work of meaning-making alone. This provides yet another psychological advantage for medical trainees and professionals who continually operate under severe time constraints. Dense text, comprising many words and complex sentence structures, can seem overwhelming when one wants to understand ideas both clearly and quickly. The same can be true of flow charts and figures whose details are so granular that they prompt a busy professional to crave a straightforward verbal summary of high-yield information. By contrast, the relative succinctness of comics text, which "can communicate in a panel that is 2 inches by 2 inches in size something that might take 3 pages in some circumstances to describe by writing" [5], seems user-friendly, and the icon, or "any image used to represent a person, place, thing, or idea," can resonate with readers because of its universality [6]. Consider, for instance, how a smiley face can prompt similar understanding—and perhaps feeling—in people of different backgrounds, ethnicities, and sexes. The smiley face is not specific to any one group of people; rather, it is readily identifiable as universally human. In short, according to Michael Green, the comic medium's "visual aspect helps [medical] students become more careful observers, discerning hidden messages and nonverbal cues when interacting with patients" [5]. Perhaps most important, as readers encounter the verbal and visual together, both the left and right hemispheres of the brain are engaged, which can enhance both cognitive and affective learning [7].

Teaching Graphic Pathographies

Visual thinking strategies (VTS) is a helpful approach to teaching graphic pathographies. The beauty of VTS is its seeming simplicity that can nevertheless lead to rich discovery, discussion, and insight [8]. VTS poses three basic questions:

- 1. What's going on in this piece?
- 2. What do you see that makes you think that?
- 3. What more can we find?

The process allows one to begin with intuition, a "gut feeling" about what's happening. The second question shifts attention to careful observation, finding evidence to support intuition. This, in turn, leads to discussions about interpretation, as one viewer claims that a given detail means something and another disagrees and suggests an alternative meaning. The VTS approach mirrors that of experienced clinicians. Consider the following panel as an example of how one might use VTS to facilitate students' understanding of a patient and her circumstances [9].



Figure 1. P.W. Smith, "Graphic Pathography in the Classroom and the Clinic: A Case Study," page 99, from *Graphic Medicine Manifesto*, 2015. Copyright © 2015 by The Pennsylvania State University Press. Reprinted by permission of The Pennsylvania State University Press.

When the first author (KRM) uses this panel with trainees, she modifies VTS a bit and begins by asking, "How does this make you feel?" Responses center around discomfort and fear and lead to the next question, "What's going on here?" A collective "aha" moment occurs when one person mentions the small ribbon on the right lapel of the patient's robe: students instantly understand that the story depicted in the panel has something to do with breast cancer. They understand the patient's fear, noting her wide eyes shadowed in dark circles, and the sweat and nervous tapping of feet, both of which are suggested by *emanata*, lines or words that protrude from a character or object to show what's going on physically or internally. Students note that the patient is holding a magazine upside down and that humanoid shadows flank her on either side. She's not really reading the magazine, nor is she aware of the people beside her; she can concentrate on nothing but the anxiety coursing through her body that's lost in an oversized robe, the garment that defines her current identity as a vulnerable patient.

In her autobiographical *Cancer Vixen: A True Story* [10], Marisa Acocella Marchetto depicts herself (and her mother) similarly stunned and afraid as a physician explains an upcoming biopsy. A single panel features two women with bulging eyes sitting across from a physician who is seated behind a desk. A text bubble above the physician contains four lines of scribble, each of which contains a single word or phrase: "cancer," "lumpectomy," "may not be invasive," and "lymph nodes," respectively. A text box along the top of the panel reads, "Before the dreaded core biopsy, Dr. Mills fills us in." And at the bottom, another text box reads: "The last doctor's visit without a tape recorder" [11].

Examining graphic pathographies via VTS can remind students and physicians of the terror patients sometimes feel when faced with an overwhelming diagnosis, as is the case in Smith's and Marchetto's panels. Comprehending this truth might inspire empathy for patients or, when feeling isn't possible, a *practice* of empathy—calling a patient with test results as soon as they are available, for example, instead of waiting until the end of the workday. The panels can also provide insight into the processes of clinical medicine. From the bug-eyed gaze of Marchetto's characters and the squiggly lines in the central text bubble, students immediately grasp that the patient is hearing—or at least registering or comprehending—almost nothing of what she is being told. The text box at the bottom underscores the message that consenting a patient is not always as effective as one hopes it will be. The patient herself knows that she will need to record what her physician says in the future so that she can listen to it over and over until it sinks in and makes sense.

Using Graphic Pathographies with Patients

Panels like these have important potential benefits for patients as well as medical professionals. For one thing, these first-person perspectives of illness can provide a patient with a sense of community: "other people know what I feel right now; they have survived, and I can, too." Cultivating a sense of community is a primary goal of support

groups, of course, but many people are not comfortable sharing feelings or intimate details of their illness with strangers. Indeed, groups that are meant to provide support sometimes ironically make people feel even more vulnerable when, for instance, members of the group share bad experiences, relapse, or even die [11].

A benefit of support groups that graphic pathographies also provide is helpful information to <u>educate and empower</u> readers. For example, while Marchetto's comic serves as a cautionary tale about the challenges of meaningful informed consent, it also, as it turns out, can actually help facilitate informed consent. Elsewhere in the pathography, Marchetto presents a series of panels that explain—and raise weighty questions about—the extravasation that can occur during chemotherapy. While patients might be told that chemicals can leak and damage tissue, the comic conveys specific implications of what that possibility might look like in real life. For Marchetto, this single side effect could cause permanent disability because she draws cartoons for a living [10]. Fuller comprehension of the implications of extravasation might suggest to a reader of *Cancer Vixen* critical questions worth pursuing with her own physician before beginning treatment.

Peter Dunlap-Shohl provides another example of how graphic pathographies can empower patients in practical ways. In *My Degeneration: A Journey Through Parkinson's* [12], he provides a full-page panel of "strategies to keep you moving" for those with Parkinson's disease.



Figure 2. Dunlap-Shohl P, "Walk This Way: Strategies to Keep You Moving," page 35, from *My Degeneration: A Journey Through Parkinson's*, 2015. Copyright © 2015 by The Pennsylvania State University Press. Reprinted by permission of The Pennsylvania State University Press.

The sequential pictures essentially create a how-to guide for practicing the various forms of walking, and the words add helpful context, clarification, and caution. As we see from Marchetto's and Dunlap-Shohl's work, readers can learn practical, even technical, information in the privacy of their own homes as they view panels at their own pace. They can think about what they see, they can research terminology, and they can take the book with them to their next doctor's appointment to ask for clarification—all of which can contribute to meaningful informed consent.

Graphic Pathographies and End-of-Life Decision Making

Most graphic pathographies touch, in some way, on mortality—likely because the illness experiences have been profound enough to impel people to tell their stories in the first place. Understandably, most people find discussions about dying and death difficult and distressing. Sharon Rosenzweig illustrates family members' "dis-ease" in "Judgment Call" [13].

Figure 3.

Panel 3 from "Annals Graphic Medicine—Judgment Call," by Sharon Rosenzweig [13]

Rosenzweig draws viewers into a vortex of jumbled, contradictory emotions in the center section of the panel, such that the reader vicariously participates in her anxiety. The reader is unmoored, unsure how to move through the panel—figuratively mirroring the lack of direction Rosenzweig experiences: the expected left-to-right, top-to-bottom process of reading does not hold here. In resonating with the chaos that Rosenzweig depicts, patients and family members might feel a sense of community, while physicians might be reminded anew of the need for empathy when dealing with exhausted families.

Despite the emotional challenges that come with these end-of-life conversations, seasoned physicians know that they are critical for competent and compassionate care of the whole person. In figure 4, Michael J. Green's autobiographical "Betty P." [14], which Green initially wrote as a poem for the Penn State Hershey Physicians Writers Group that the first author (KRM) founded and hosts, illustrates the damage that can result to both patient *and* doctor when these conversations don't happen.

Figure 4.

Panel 3 from "*Annals* Graphic Medicine—Betty P.," written by Michael J. Green and illustrated Ray Rieck [14]

Reading that this terminally ill woman has been abandoned by her children and seeing the anguish etched in her face, the reader is able to view the situation through the doctors' eyes. Surely, allowing a merciful death would be better than intervening and thereby prolonging the woman's agony. When the patient codes and the intern, Green, must administer CPR, the reader vicariously participates in his agony as well [14].

Figure 5.

Panel 5 from "*Annals* Graphic Medicine—Betty P.," written by Michael J. Green and illustrated Ray Rieck [14]

The repulsion Green feels as he batters her frail body is surpassed only by the guilt he feels for violating his own moral code. Forced by circumstance to disobey his oath to

"First, do no harm," Green is haunted by guilt and shame—so much so that he not only recounts this story to his younger colleague, but also creates this comic years after the fact. In this way, "Betty P." is an excellent tool to use with medical students to impress upon them the importance of having <u>end-of-life conversations</u>, no matter how difficult they might be. "Betty P." can also be a helpful tool to use with patients and family members to impress upon them the importance of making their wishes known before it's too late.

Conclusion

Graphic pathographies, like any other tool, are not a panacea for learning or for teaching. The greatest impediment to their wholesale use in clinical medicine is likely the misguided perception that "comics are for kids" and therefore have little to offer participants in the high-stakes arena of managing serious disease. However, as the recent shift toward using comics to further both patients' and physicians' understanding of illness suggests, the field of graphic medicine has important implications for the empathic practice of whole-person medicine.

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Kimberly R. Myers, MA, PhD, is an associate professor of humanities and medicine at Penn State College of Medicine in Hershey, Pennsylvania. She has published in professional journals including *JAMA*, *British Medical Journal*, *Annals of Internal Medicine*, and *Academic Medicine* and lay periodicals including the *Atlantic* and the *Chronicle of Higher Education*. Dr. Myers is editor of three international, multidisciplinary collections and coauthor of *Graphic Medicine Manifesto* (Pennsylvania State University Press, 2015).

Michael D. F. Goldenberg, MA, is a second-year medical student at Penn State College of Medicine in Hershey, Pennsylvania. He completed a master of arts degree in comparative literature at the Pennsylvania State University, with a thesis focusing on the use of comics in medical education and patient care.

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MEDICINE AND SOCIETY

Parasites! Graphic Exploration of Tropical Disease Drug Development Susan M. Squier, PhD

Abstract

Parasites!, a 2010 comic sponsored by the Wellcome Trust Centre for Molecular Parasitology, demonstrates that a graphic narrative can play a role in energizing public debate. Part of the genre known as graphic medicine—comics about illness, treatment, disability, and caregiving— *Parasites!* is intended to educate readers of all ages about illnesses less known in the developed world. Two visual strategies in particular enable the comic to offer an alternative and aesthetic response to questions about developing drugs to treat tropical diseases for profit. By including visuals and text, and not just one of these formats, viewers must reorient themselves aesthetically and epistemologically to ethical, social, cultural, and political structures that adversely affect human health.

Introduction

Tropical diseases such as sleeping sickness, <u>malaria</u>, and kala-azar that primarily affect populations too poor to pay for drug treatment pose a significant bioethical question. How should priorities be established for the funding of research and development of the drugs required for treatment when no profitable market for them exists? Arguing that more bioethical attention should be focused on the tension between the need for such drugs and the capacity for users to pay for them, Gericke et al. identify open public debate as a crucial part of the deliberative process for establishing equitable means of setting priorities for funding research for unprofitable drugs [1]. Conventional modes of evaluating economic priorities should be enhanced, Gericke et al. argue, by attention to the ethical issues involved in the process of setting funding priorities as well as their profitability. In this essay, I examine one means of raising awareness of ethical issues and catalyzing debate about the funding of drug research for tropical diseases: graphic medicine. In the graphic narrative *Parasites!*, the aesthetic combination of text and image encourages readers to explore new ways of thinking about the ethical, social, cultural, and political structures that adversely affect human health.

Parasites!, a 2010 comic written by Jamie Hall and Edward Ross and illustrated by Edward Ross, demonstrates that a graphic narrative can play a role in energizing public debate [2]. Part of the genre known as graphic medicine—comics about illness, treatment, disability, and caregiving—*Parasites!* is intended to <u>educate readers</u> of all

ages about illnesses less known in the developed world [3]. One of three comics created by the Wellcome Trust Centre for Molecular Parasitology (WTCMP) as part of its public engagement program, *Parasites!* was followed in 2012 by *Malaria: The Battle against a Microscopic Killer* [4] and in 2016 by *Sleeping Sickness: The Fight against a Nightmarish Disease* [5]. While all of these comics are fascinating, *Parasites!* deserves close attention as the first one created for the WTCMP's public engagement program. The textual and visual narrative strategies used by authors Hall and Ross, and the illustrations by Ross, evidently impressed the WTCMP enough to launch this public engagement project and to motivate the creation of the comics that followed.

Visual Strategies for Engagement, Education, and Ethical Analysis

Comics intended for public outreach and education must often perform a balancing act between didacticism and inspiration. *Parasites*! marries visual and text-based storytelling to hit that balance. The simplified illustration of scientific concepts, use of storytelling and narratives, and focus on central characters with whom readers can identify—often real researchers at the WTCMP—are all part of its strategies for engaging a diverse public. The text in speech balloons, text boxes, and captions covers a brief history of parasitology and the nature of the three parasites under study. It also expresses the goal of the individual scientists and the WTCMP as a whole to remove a "major obstacle to development" by finding "new ways to control, treat, and eventually eradicate these diseases" [6]. Like the speech of the researchers it includes as characters, the narrative uses direct declarative prose and, judiciously, bold print to convey the challenges posed by an attempt to control parasites. We learn of the biological processes triggered by three parasites under consideration—Plasmodium, Trypanosoma brucei, and Leishmania—as well as the mechanisms by which they cause malaria, sleeping sickness, and kala-azar. We also learn about the importance of Scots David Livingston, William Leishman, and Patrick Manson in the study of tropical diseases. And we learn of the many strategies contemporary researchers use to study parasites: from the use of fluorescent dye to tag their genes to the process of gene sequencing, enabling the comparison of entire genomes of different parasite strains. A tension between research as pure science and research to aid the global development project is evident in both the textual narrative and the visual images, as I will go on to demonstrate.

Aesthetic and Ethical Analysis in Parasites!

While the WTCMP has said that it created this comic to provide educational outreach, it also provides a visual platform for ethical and social analysis of drug development research [7]. Comics lend themselves to such ethical and social analysis, since the medium has a long tradition of speaking for the outsider [8]. *Parasites!* joins that tradition by voicing and visualizing the experiences not only of Western parasitologists but also of African peoples far from the dominant economic, political, and social cultures of Europe. Two visual strategies in particular enable the comic to express complex ambiguous and emotionally-charged issues: its control of perspective and its deployment of scale, by

which objects are ordered in a sequence or hierarchy. Just as changing the angle from which we look at something can let us see it anew, so, too, reevaluating the scale at which we encounter a concept, person, or process can enable us to revise our response to it. The aesthetic strategies of the comic draw the reader into an exploration of ethics, moving her to challenge assumptions in the text because of her emotional engagement with the images.



Figure 1. Excerpt from *Parasites!*, by Jamie Hall, Rachel E. Morris, and Edward Ross. © 2010 Jamie Hall, Rachel E. Morris, Edward Ross, and the Wellcome Trust Centre for Molecular Parasitology. Reprinted by permission of the Wellcome Trust Centre for Molecular Parasitology.

In figure 1, we can see how the ethical, social, and political issues central to parasitology at the WTCMP are explained textually and embodied visually. The first panel on the page, picturing a white woman standing against a large array of neatly arranged pharmaceuticals of all kinds, explains the problem of drug development for tropical diseases: "Parasitic diseases mostly affect poor people in developing countries, and so they are generally neglected by drugs companies." In the second panel, that dry summary is replaced by an image compactly contrasting that Western and Northern world of plenitude and order to one of stark need. The statement describing the problem of unprofitable drug research initially seems unarguable, even inevitable: "It's bad business spending time and money producing treatments that people can't afford." The ethical justifiability of this purely economic rationale is challenged by the accompanying image, however. At the panel's center, a brown-skinned hand curls tensely around a green and blue capsule. This hand—so distinctly human and so full of agony—divides two columns of text that flatly sum up the brutal calculus at work in the research and development of unprofitable drugs: "\$1 billion: cost to bring a new drug to market," and "50%: proportion of people in developing countries living on less than \$2 a day." The ethical sleight of hand in the top right panel is exposed in the visual image of the grasping hand. The text labels the decision not to make a drug available to patients "bad business," a label that obscures the company's ethical obligation to patients and the clinicians who serve them to develop a drug, even an unprofitable one, targeted to a specific population if a company has other profitable, or even lucrative, revenue streams. This distinction between viability and profitability presented textually in the top right panel disappears in the bottom right panel, where we learn that the WTCMP researchers ignore economic considerations and merely study "what's important and interesting."

This shift to a close-focus perspective on the human bodies of those affected offers an alternative to the monetary rationale for the lack of drug development for tropical diseases, one that puts social, cultural, and ethical categories at the center. In the next panel, this new perspective is conveyed by the disruption of visual scale. A young woman who might suffer from sleeping sickness stares in horror at a bottle of medicine. The woman is positioned on the left of the bottle, while to the right, at a surprisingly large scale, looms a large purple and pink trypanosome. The bottle's skull and crossbones icon and POISON label echo the text above the bottle: "Most of the drugs developed to treat sleeping sickness are relics from the days of Empire. Melarsoprol, still commonly used today, is based on Arsenic and the principle that the drug will kill the parasite before it kills the patient." The arsenic-based drug melarsoprol, one of only four drugs available to treat sleeping sickness (the others being pentamidine, suramin, and effornithine) is currently prescribed only for second-stage sleeping sickness [9]. Yet though suramin, a drug prescribed for the earlier stage of the disease, is without arsenic, it, too, exemplifies what we might call the ethical, social, and political side effects of drug treatment.

The History of Unprofitable Drug Development

Why are these sleeping sickness drugs "relics from the days of Empire"? The history of African trypanosomiasis, or sleeping sickness, is interwoven with the African slave trade in the eighteenth and nineteenth centuries. The many deaths it caused were viewed by the slave traders as property losses, leading them to call for increased research on the disease [9, 10]. Sleeping sickness still ravaged Africa at the turn of the twentieth century, killing an estimated 300,000 and 500,000 people in the Congo Basin and in the Busoga focus in Uganda and Kenya, respectively, between 1896 and 1906 [10]. As with the deaths in the slave trade, this later epidemic also led the colonial administrators to call for a cure [10]. Thus the history of colonial oppression is intimately interwoven with the history of drug development.

Just as the slave traders were driven by a profit motive in seeking a cure for the disease (to reduce property losses), so a different kind of profit motive appeared in the early twentieth century as countries and emerging corporations jostled for extractive profits from African territories. By 1917, the Bayer Company had succeeded in synthesizing a compound it called Bayer 205 or, with nationalistic pride, Germanin™ (also known as suramin) [9]. Despite its breakthrough efficacy, this drug was not immediately made available to African territories, although sleeping sickness remained a terrible problem there [9]. Instead, realizing that this drug could be of great importance to nations intending to profit from their African colonies, the Bayer Company approached the British government and attempted to trade the drug formula for the return of Germany's African territories [9]. These were the colonies lost during the "scramble for Africa," the period in which Africa was occupied, divided into territories, and colonized by European nations between 1881 and 1914 [11]. When the British government refused to carry out the exchange, obviously valuing their colonial possessions more than the health of Africans, the Bayer Company kept the formula secret. In 1924, it was published by Frenchman Ernest Fourneau, but Bayer only confirmed it as accurate in 1928 [9]. Such frequently imperialist and oppressive relations between governments, emerging corporations, European scientists, and African peoples [10] are the imperial relics referenced in Parasites!

When we return to the panel in which the frightened woman, the trypanosome parasite, and the bottle of arsenical drug appear at the same visual scale, we see how the image captures the ethical problem at the core of the unprofitable drug dilemma: the focus on profit that reduces people, parasites, and pills to the same level. The tug-of-war between the United Kingdom (UK) and Germany over Germanin is a historically relevant ethical point, demonstrating the harsh economic calculus that dismissed the welfare of the African peoples in the struggle for valuable territories and extractive profits. The issue still has ethical relevance now, as the Drugs for Neglected Diseases Working Group (DND) of Médecins sans Frontières (Doctors Without Borders) argued in 2002: it advocated "an international not-for-profit initiative that would focus on drug

development projects for the most neglected diseases" in order to "remove the process of researching and developing life-saving drugs from a market-driven logic" [12].

After exposing the core problem in drug development for tropical diseases—target populations that are too poor to pay for drug treatment and the ethical failure to shelter the process of drug development from market-driven logic—*Parasites*! broaches the question of whether alternatives exist to for-profit research as a means of drug discovery. The next two panels purport to give us our answer. In the first, we are back in Glasgow at the WTCMP, where we peek over the shoulder of a young researcher who explains that he studies "what's important and interesting, even if it's not financially profitable." Then, against a silhouette backdrop of nighttime Glasgow, a white-haired researcher explains his passion for the work of the WTCMP: researchers, "fascinated ... and driven by a desire to understand" rather than the profit motive, study these parasites in "labs, clinics and field stations around the world" with the hope of "controlling these parasites and curing the terrible diseases they cause." Yet even as these concluding panels of the comic celebrate science for science's sake, they shy away from formulating the more far-reaching and complex issues that structure the development of unprofitable drugs: the selection of which scientific research gets done, for whom, and in what economic, ethical, and political context.

Conclusion

By including visual images that require us as viewers to reorient ourselves ontologically and epistemologically, *Parasites!* illuminates the structural features of imperialist oppression that adversely affect human health. As we look at these images, we are forced to ask ourselves questions that transcend the economic factors that limit access to health care: Where should we place these parasitic diseases in the scale of scientific knowledge? And where should we place their victims in the scale of human life? By providing the context in which readers can explore these questions, *Parasites!* enriches the public debate about global priority-setting for drug research funding and draws attention to previously unexamined assumptions about obligations of drug developers as global citizens and the impact of labeling pharmaceutical markets as "viable" or "profitable."

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Susan M. Squier, PhD, is Brill Professor Emerita of English and women's, gender, and sexuality studies at Pennsylvania State University in University Park, Pennsylvania, and an Einstein Visiting Fellow at Freie Universität, Berlin, where she is a collaborator on the PathoGraphics Project. The co-author of *Graphic Medicine Manifesto* (Pennsylvania State University Press, 2015) and co-editor of the Graphic Medicine Book Series at the Pennsylvania State University Press, she is the author of *Liminal Lives: Imagining the Human at the Frontiers of Biomedicine* (Duke University Press, 2003) and *Epigenetic Landscapes: Drawings as Metaphor* (Duke University Press, 2017).

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MEDICINE AND SOCIETY

How Should We Judge the Ethics of Illustrations in Graphic Medicine Novels?

Linda S. Raphael, MA, PhD, and Madden Rowell, MD

Abstract

This essay argues that we should judge the illustrations in a graphic novel (often a memoir) in the context of the entire work. Judging a work on its emotive effects and the values it expresses, we can consider the ways a graphic novel represents the experience of illness, disability, or injury.

Introduction

Reading a graphic novel involves a lot of work; images and words can give similar messages or suggest different interpretations. The reader needs to pay attention to the "gutter"—the empty spaces between frames that the reader almost unconsciously fills—and take note of the size of frames. Artists create splash pages in which only one scene or image is depicted; they might organize the page with similarly sized panels or large and small ones. Generally, large panels indicate that the image or the words are especially important.

Graphic medicine novels feature characters who often experience illness or injury, which therefore makes yet another demand on a reader. That demand—that the reader judge the ethical import of the drawings and words—is complex. For example, Kathryn Harrison's confessional memoir *The Kiss: A Memoir* [1], can be analyzed in terms of whether Harrison seeks to sensationalize her sexual relationship with her father or seeks understanding of her experience. Readers might ask similar questions about Alison Bechdel's *Fun Home: A Family Tragicomic* [2], a graphic novel that explores her father's sexual relationships with his high school students, his apparent suicide, and her own "coming out." The questions we ask can be asked of graphic and nongraphic texts alike; however, the illustrations raise and often answer different questions than nongraphic text.

In this essay, we argue that three principles, suggested by James Phelan in *Living to Tell about It: A Rhetoric and Ethics of Character Narration* [3], prove to be useful in judging the ethical nature of not only "words-alone" texts but also graphic novels:

- 1. *The cognitive dimension.* What do we understand and how do we understand it?
- 2. The emotive dimension. What do we feel, and how do those feelings come about?

3. *The ethical dimension*. What are we asked to value in these stories, how do these judgments come about, and how do we respond to being asked to take on these values and make these judgments?

The responses to these questions might differ among readers; however, we believe that the above considerations are helpful to anyone who attempts to make the complex judgments graphic novels ask of us.

The Author as Central Character in the Graphic Novel or Memoir

David Small's autography, *Stitches: A Memoir* [4], raises some questions about how we understand the revelation of David's parents' and his grandmother's mistreatment of him. We know that David's childhood was unhappy; his patents and his grandmother mistreated him; his mother was an alcoholic who was secretly a lesbian; his father was a radiologist whose decision to give David x-ray treatments for his throat problems led to throat cancer. The reader likely feels angry at the parents and grandmother and sad for David. As we see in figures 1-3, the small child is helpless in the face of cruel or careless adults.

Cognitive dimension. The varied size of the panels and frequent absence of words illuminate some of the above meanings. In figure 1, where David's maternal grandmother drags him up the stairs by his wrists, the full panel indicates, "This is very important!" Figure 2, a half-page panel, shows David alone on the bathroom floor immediately afterwards. Figure 3, a smaller panel that offers a close-up of the faces of David and his father when the former complains about his grandmother, focuses the reader on the father's rage. The story is not only about the abuse David suffered at the hands of his grandmother but also about his radiologist father administering x-ray treatments to his throat, which caused him to lose his voice. Clearly, visual over verbal expression "speaks" to David's experiences.



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Figure 1. Excerpted from *Stitches* by David Small. Copyright © 2009 by David Small. With permission of the publisher, W. W. Norton & Company, Inc. All rights reserved.



Figure 2. Excerpted from *Stitches* by David Small. Copyright © 2009 by David Small. With permission of the publisher, W. W. Norton & Company, Inc. All rights reserved.



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Figure 3. Excerpted from *Stitches* by David Small. Copyright © 2009 by David Small. With permission of the publisher, W. W. Norton & Company, Inc. All rights reserved.

Emotive dimension. These frames depict emotions of fear and anger; the values that are represented by their absence are respect and restraint. The visual representation of the small child next to his father, whose large hands encompass almost all of David's upper back, reinforces the sense of helplessness that David's tale evokes. David only occasionally narrates his story outside the dialogue in the frames, but emotions, values, and judgments find expression.

Ethical dimension. Through illustrations, David is able to avoid using a child's language to report what would be beyond his younger self's ability to express; the reader enters into

the child's experience through visual depictions of the child's fear, the grandmother's cruelty, and the father's rage without attributing to the young David thoughts beyond his expressive capability or, alternatively, inserting David's adult judgment. The reader therefore makes her own ethical judgments of David's situation. Take, for example, David's father's medical treatment of his son. Generally speaking, physicians are advised against treating their own family members [5]. The ethical question of whether David's father did the right thing by administering radiation to his throat cannot be answered solely by the effects of the radiation since outcomes do not necessarily determine the ethics of an action. Rather, David's father's raging behavior, depicted in figure 3, suggests that his medical treatment of his son may have been as poorly considered as his general treatment of his son.

Interpreting the Patient's Experience

Although it seems obvious that the patient is the central person in her illness narrative, well-meaning physicians might lose sight of this fact as they seek to provide the best treatment they can based on their own medical knowledge and that of other physicians. In a recent instance, the second author (MR) noted that her attending physician coached a medical student on her team not to present patients' explanation for their symptoms but simply the symptoms themselves: "We know that her lack of appetite is from her cancer-related pain, not from sitting in her hospital bed like she said to you. Patients always come up with explanations for their symptoms ... that aren't always correct." The resident worried that the practice of separating patients' explanations from their symptoms has become second nature. She noted that she had written "patient reports subjective fever, but temperature afebrile on exam" countless times. She expressed concern over being constantly reminded to separate the subjective from the objective and, in some cases, to ignore the patient's subjective experience altogether.

Graphic novels take the patient's experience of illness and infuse it directly into the medium of expression. The narrative of a patient or family member cannot be manipulated with words or transformed into medical jargon; it is there in 2D without apology. In *Mom's Cancer* [6], after a caption that reads, "The exams begin," Brian Fies breaks the physical exam into many small frames, each containing an action and a command (see figure 4).These frames portray the patient's subjective experience of the physical exam, highlighting how, for the patient, these mysterious movements can reduce her to only a body in our search for objective data.



Figure 4. "The Exams Begin," from *Mom's Cancer*, by Brian Fies. © 2006 Brian Fies. Reprinted by permission of Brian Fies.

These frames suggest the subtle indignities that Mom experiences without her authorson's interpretation. Drawing only the foot suggests the treatment of a patient as a bundle of parts. The images call for empathic emotions; they highlight the value of <u>empathic treatment</u> of the other—missing here—by carefully informing a person about things being done to her body. Graphic novels are thus an important reminder to clinicians that subjective experience and objective data are not always so cleanly divided into two separate entities. While patients might feel objectified, our objective data are colored by the language we use, our level of fatigue or compassion in any given moment, our teachers, and our culture.

Health Care Professionals as Graphic Artists

The graphic novels of two health care professionals, MK Czerwiec and Ian Williams, offer yet other ways to think about the ethical import of illustrations. In *Taking Turns: Stories from HIV/AIDS Unit 371* [7], Czerwiec records her experience working in a hospital AIDS unit in 1994 in words and in illustrations she describes as "simple." Yet her recounting of the experience is anything but simple. In fact, her style tends to make the characters look similar, suggesting the complexity of the relationship. Czerwiec's book expresses empathy for her patients and pain at losing them (see figures 5 and 6). Perhaps this is part of "taking turns." Often patients are surprised and even dismayed when their clinicians become ill or die. They see them as invulnerable, a view that is sometimes matched by that of the clinician herself. In *Taking Turns* this view is overturned.



Figure 5. Excerpted from *Taking Turns: Stories from HIV/AIDS Care Unit 371*, by MK Czerwiec. © 2017 MK Czerwiec. Reprinted by permission of MK Czerwiec.

When Czerwiec's patient Tim dies, Czerwiec stands at his bed expressing in words the absence of a person who still seems so immediately present (see figure 6). The illustration symbolizes loss and encourages the reader to value the friendship that Czerwiec and Tim shared. The novel thus expresses values for human communication, closeness, and the ways that deep caring about others can play a significant role in the lives of those who give the care as well as those who receive it.



Figure 6. Excerpted from *Taking Turns: Stories from HIV/AIDS Care Unit 371*, by MK Czerwiec. © 2017 MK Czerwiec. Reprinted by permission of MK Czerwiec.

The illustrations of both Ian Williams (see figure 7) and Czerwiec bring to mind the words of the German cartoonist, Erich Ohser, who was internationally famous for his comic strips in the 1930s. He spoke about the aesthetics of comics in his 1943 *In Defense of the Art of Drawing*.

If you draw, the world becomes more beautiful, far more beautiful. Trees that used to be just scrub suddenly reveal their form. Animals that were ugly make you see their beauty. If you then go for a walk, you'll be amazed how different everything can look. Less and less is ugly if every day you recognize beautiful forms in ugliness and learn to love them.... A small drawing that comes from the eye and the heart is worth more than sixty square feet of inhibited, dishonest hack work [8].

While Czerwiec's drawings offer a simplistic beauty, Williams, a physician, draws more elaborately. In *The Bad Doctor: The Troubled Life and Times of Dr. Iwan James* [9], the story of a physician who has experienced symptoms of obsessive-compulsive disorder since childhood, Williams includes a complex drawing that seems to draw on the Kabbalah's ten *Sefirot* or manifestations of God [10] by offering the reader multiple representations of illness by the patient and the doctor himself (see figure 7). The tension between the mortal and the infinite, represented in the Kabbalah and in Williams's drawing, corresponds to Ohser's idea that the world is made more beautiful in sincere illustrations.


Figure 7. Excerpted from *The Bad Doctor: The Troubled Life and Times of Dr. Iwan James*, by Ian Williams. © 2014 Ian Williams. Reprinted by permission of Ian Williams.

Conclusion

We have offered examples in this essay of how illustrations in graphic medicine texts create or augment meanings that the narrator could not express (*Stitches*), experiences that patients endure (*Mom's Cancer*), and the relationship between a patient and nurse (*Taking Turns*). Each of the graphic medicine novels to which we refer has ethical implications for patient care and the patient-physician relationship, and, in each case, the illustrations do much of the work in developing these ethical implications.

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Linda S. Raphael, MA, PhD, is the director of the program in medical humanities at the George Washington University School of Medicine in Washington, DC. She is the author of *Narrative Skepticism: Moral Agency and Representations of Consciousness in Fiction* (American University Press, 2001), *When Night Fell, an Anthology of Holocaust Stories* (Rutgers University Press, 1999), and articles on literature and on medicine and humanities.

Madden Rowell, MD, is a resident in primary care at Yale University School of Medicine in New Haven, Connecticut. She is a graduate of the George Washington University School of Medicine and Scripps College.

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HISTORY OF MEDICINE

Of Cornopleezeepi and Party Poopers: A Brief History of Physicians in Comics Carol Tilley, PhD

Abstract

The representations of physicians and medical practice found in comic strips, comic books, and graphic novels throughout the past century reflect broader representational trends in popular visual media. Drawing on examples including Winsor McCay's *Dream of the Rarebit Fiend*, the superhero comics character Stephen Strange/Doctor Strange, and contemporary graphic medicine, this article outlines the shifting models for depicting physicians and medical ethics in comics. It concludes that contemporary representations are often more realistic and nuanced, although gender and racial diversity along with diversity in medical specializations remains problematic.

Introduction

Cartoonist Winsor McCay scattered encounters with doctors throughout his surrealist fantasy newspaper comic strip, *Dream of the Rarebit Fiend*, which initially ran from 1904 through 1911 [1]. In one of the dailies, a man is shot and is skillfully saved in surgery when the physician removes the bullet from his "kopocolus" located near the "diastacutis" [2]. In another, after a woman's corn sprouts stalks, her physician warns her that removing it will cause her to bleed to death, as it's a "cornopleezeepi." He advises her to water it and harvest the resulting ears [3]. These encounters happen only in dreams, induced by the dreamer's consumption of a Welsh rarebit before bedtime. Still, they serve as early examples of popular comics representations of physicians: a bit quackish, they are nonetheless erudite diagnosticians and capable clinicians—at least in the dreamers' minds—who use an arcane language as a demonstration of their authority.

Although physicians appeared intermittently in other comic strips in the 1910s and 1920s, not until the advent of comic books in the 1930s did physicians as characters in comic books and newspaper strips become a more regular occurrence. This essay offers a brief and selective history of some of the broad changes in the representation of physicians in comics originally published in English from 1940 until today. It highlights both the changing conceptions of the profession and the integration of medical ethics into comics storytelling and concludes with recommendations for increasing demographic and professional diversity in future comics portrayals.

Representation of Physicians as Beneficent

"Dr. Mid-Nite," a character originating in *All-American Comics* in 1941 but continuing in various forms through today, is an example of the beneficence and technical facilities of early comic book physicians. Dr. Charles McNider, Dr. Mid-Nite's real identity, is presented as a just and heroic figure, "on the verge of a great discovery ... [of] a serum that will save thousands of lives" [4]. A police officer interrupts his work to plead with him to save the life of a witness in a mobster's trial. McNider's beneficent approach to medicine means he is "never too busy to do a good deed" [4], but when one of the mobster's henchmen sees him tending to the still-living witness, the henchman lobs a grenade into the room. Valiant but unnamed surgeons save McNider, although he seems to be completely blind. When an owl crashes through his window one evening, McNider realizes he can see in the dark, and thus begins his career as the crime-fighting (and still medicine-practicing) Dr. Mid-Nite, accompanied by his sidekick Hooty the owl.

As seemingly ridiculous as the examples of Dr. Mid-Nite and the "Rarebit Fiend" physicians might seem today, they helped establish models for comics' portrayals of physicians—models reflected by other popular media such as film and <u>television</u>. Sociologist Deborah Lupton asserts, "Analyses of the depiction of doctors on American television dramas have found that they were generally portrayed as successful, benevolent, knowledgeable and authoritative, with almost mystical powers to dominate and control the lives of others" [5]. These two comics representations also illustrate a cultural shift in the perceptions of physicians and medicine. Medicine was a site of increasing professionalization and technologizing in the early 20th century, but popular media were slow to move from their perceptions of physicians as eccentric purveyors of questionable remedies [6]. The 1937 film *Internes Can't Take Money* (based on a 1936 story by Frederick Schiller Faust, using the pseudonym Max Brand), which introduced Dr. James Kildare, established a new model for portraying physicians in popular media.

The physician was not to be seen simply as an educated individual who had learned a valuable trade. Instead, he was to be seen as a member of a modern elect: a contemporary knight whose painful movement through the lists of training had shown that he had the heroic stature necessary to link a compassionate nature to the wonders of healing technology [7].

In this paradigm—exemplified by Kildare as well as Dr. Mid-Nite—writers seldom needed to make explicit significant ethical quandaries because characters embodied principles of justice and beneficence, making the outcomes predictable.

Portraying physicians as altruistic and at the vanguard of medical technologies and discoveries was not limited to fictional characters. In a 1941 issue of *True Comics*, an educationally-focused comics serial from the publishers of *Parents Magazine*, a story on

physician, microbiologist, and Nobel laureate Robert Koch, for example, portrays him as toiling ceaselessly to find the cure for anthrax, resulting in a "great discovery" [8]. Koch is rewarded with a prestigious professorship and the Nobel for his "genius" [9]. Because he "discovered the germ that caused cholera ... [and] explained to the rulers of the country how to destroy it" [10], the comic implies that the compassionate, technology-wielding hero Koch almost single-handedly saved the people of India. Similarly, a 1943 story in *Real Life Comics* idealizes the life and legacy of Dr. Wilfred Grenfell [11]. Grenfell is first shown as a child, possessing a singular awareness that sailors lack adequate medical assistance when at sea. As a young doctor, Grenfell receives an opportunity to work with North Sea fisherman, immediately assents to his destiny—"It's what I've always wanted to do! Count me in!"—and embarks on a series of "acts of heroism" [12]. Grenfell faces incredible dangers and applies an almost superhuman work ethic, acting unselfishly and applying technological ingenuity to solve the medical problems facing the communities he served.

Comics Physicians Begin to Explore Ethical Dilemmas

Gradually comics began portraying physicians in more nuanced ways that allowed for the depiction of ethical conundrums. Created by psychiatrist Dr. Nicholas P. Dallis under the pseudonym Dal Curtis in 1948, the newspaper comic strip physician Rex Morgan, MD, which continues in syndication today, provides a key example. In a December 1950/January 1951 arc, a nurse attempts to euthanize her severely ill father. Morgan discovers what has happened, saves the man from death, and plans to discipline the nurse. Brice Adams, another physician, criticizes Morgan's ethical approach: "The fact that Jan's father is going to die anyway seems to make no difference to either of you!" Morgan responds, "Our job is to prolong life ... not to decide when it should be terminated" [13]. The short-lived comic book series *The Young Doctors* provides other examples of ethical decision making. The series features handsome, young white physicians—surgeon Cliff Landon, psychiatrist Martin Burke, and intern Tom Brent. While it dispensed with the overt superheroism that dominated clinicians' portrayals in comics in the preceding few decades, *The Young Doctors* maintained the racial status quo of real-world medicine, in which even as of 1972, fewer than 3 percent of US medical school graduates identified as nonwhite [14]. These stories, however, occasionally showed characters wrestling with ethical dilemmas instead of inherently making ethical choices. For instance, in a story titled "The Party Pooper," Brent shirks his hospital duties to attend a party where friends have "a cute little trick lined up for" him [15]. Ultimately, his sense of duty overwhelms him at the party, and Brent rushes back to the hospital to complete his work. In another story, Landon must decide whether to divulge to police what a criminal suspect tells him on the operating table [16].

While characters such as Rex Morgan and the trio in *The Young Doctors* were portrayed in generally positive ways, Marvel Comics' Doctor Stephen Strange went against this norm. As with Dr. Mid-Nite before him, Strange, who debuted in *Strange Tales* #110 (July 1963)

and continues as a character in various Marvel publications today, transformed from human to superhero because of an accident. Strange began as an egotistical, moneygrubbing, brilliant surgeon who has to reinvent himself after an accident destroys the nerves in his hands; in the process he develops mystical powers that outstrip his surgical ones [17]. Doctor Strange entered the scene at the same time as *The Young Doctors* trio, providing an intriguing contrast to the others' relative realism: Doctor Strange's emphasis is most decidedly on "strange" rather than "doctor." Despite the lack of a medical storyline, Strange's deepest involvement with anything resembling medical ethics comes during 2007's *Civil War* story. Refusing to choose sides in a battle between superheroes who disagree whether a new government superhero registration requirement is good, Strange isolates himself. Because he fears the loss of life that might ensue were he to abandon his neutral position, Strange meditates on an outcome that "is best for all mankind … and spills the least amount of blood" [18].

Comics Physicians Become Increasingly Human

Just as onscreen images of physicians began in the 1970s to shift from idealized and infallible heroes to still heroic but imperfect humans [19], so the depictions of physicians in contemporary nonsuperhero comics veer toward portraying them as messy and fallible humans with imperfect medical knowledge. In doing so, comics can address more nuanced issues such as physician-patient relationships as well as more sympathetic portraits of physicians. David Small's memoir *Stitches: A Memoir*, for instance, portrays his radiologist father as an angry, distant man, who regularly treated Small's respiratory ailments with radiation, creating a life-altering and nearly life-ending cancer in teenage Small's throat [20]. The book raises multiple questions about physicians treating family and ethics of care. Iwan James, the rural Welsh general practitioner in Ian Williams's The Bad Doctor: The Troubled Life and Times of Dr. Iwan James, is not threatening like David Small's father [21]. Rather, he is a decent man and competent doctor whose life, both personally and professionally, has ceased to be rewarding. He also happens to have obsessive-compulsive disorder, the same as a patient he is treating, allowing him to reflect on the care he provides. As the story unfolds, the reader finds James to be an extraordinarily human clinician, not a bad one.

Physicians' everyday humanness continues as a theme in many of the comics in the *Annals of Internal Medicine*. In "Internship," for example, a confident, optimistic new intern is stumped and must rely on Google after his *first* patient requests something for her headache [22], while in "Breach of Confidentiality," a physician arrives home one day and decompresses by telling a story about a patient [23]. Near the end, she reminds her listener—revealed in the next panel to be a cat—not to tell anyone.

Conclusion

The <u>graphic medicine</u> movement of the past decade, which spurred the development of the comics described in the previous section, is poised to continue pushing

representations of physicians, medicine, and ethics toward realism. Between the 1930s and the 1980s, comics physicians tended toward technical and ethical perfection. Writing about Rex Morgan in 1972, a physician commented, "He does not need anyone, but everyone needs him. He does everything from psychiatry to surgery, and rarely makes a referral ... [he is a] fantasy of the omnipotent male" [24]. Today, as with Ian Williams's *Bad Doctor*, omnipotence is no longer a central feature, although physicians are still primarily portrayed as white males.

Thus, a basic representational challenge remains. Comics hold few positive examples of nonwhite, nonheteronormative male physicians, making it essential that health care professionals in comics reflect greater ethnic, racial, and gender diversity. Cecilia Reyes, the Puerto Rican surgeon, and Michael Twoyoungmen, an indigenous surgeon, both of whom are part of the *X-Men* universe, along with Beth Chapel, an African-American physician who assumes Dr. Mid-Nite's identity, are starting points—but only that. Likewise, comics physicians must be depicted as something other than surgeons. Surgery and trauma care are more readily visually engaging than endocrinology or geriatrics, but easy representation is no excuse for maintaining an unrealistic status quo. As the comics industry generally pushes to diversify creators, characters, and stories [25], comics that emphasize health care and medicine must also be intentional in portraying diversity. Only then will the future remain bright for representations of physicians and health care in comics.

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Carol Tilley, PhD, is an associate professor in the School of Information Sciences at the University of Illinois at Urbana-Champaign. She studies the reception of and reading practices related to comics as well as the clinically based work of psychiatrist Fredric Wertham. A 2016 Eisner Awards judge and current president-elect of the Comics Studies Society, Tilley is a frequent speaker on comics history, comics in libraries, and graphic medicine.

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IMAGES OF HEALING AND LEARNING

The Crisis in Our Neighborhood

Artwork and caption by Jason Bitterman, MD

Editor's Note: Jason Bitterman is the winner of the 2017 AMA Journal of Ethics *Conley Art of Medicine Contest.*



Figure 1. Detail from "The Crisis in Our Neighborhood," by Jason Bitterman

Media

Ink and paper.

Caption

This comic represents various clinical and ethical dimensions of the skyrocketing incidence of opioid overdose. The comic also seeks to represent the humanity of patients struggling with addiction and to highlight the importance of clinicians' roles in helping mitigate the harms of opioid dependence.

Jason Bitterman, MD, is a resident in physical medicine and rehabilitation at Rutgers New Jersey Medical School/Kessler Institute for Rehabilitation in Newark, New Jersey. His medical comics are published at <u>www.bittermensch.com</u>.

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IMAGES OF HEALING AND LEARNING

Reviewing Systems

Artwork and caption by Hannah R. Abrams

Editor's Note: Hannah R. Abrams earned honorable mention in the 2017 AMA Journal of Ethics *Conley Art of Medicine Contest.*



Figure 1. Detail from "Reviewing Systems," by Hannah Abrams

Media

This poster was created with Pages 5.6.2.

Caption

This poster represents the experience of a clinician-in-training with a diagnostic screening method typically called "review of systems." Although at times executing this method can feel onerous, it is intended to reveal key symptoms, promote inquiry, and enhance communication. It also sometimes generates unexpected and important insights, and that experience is conveyed here with a combination of text and images.

Hannah R. Abrams is a second-year medical student at Baylor College of Medicine in Houston.

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MEDICAL NARRATIVE

Representing AIDS in Comics

MK Czerwiec, RN, MA

Abstract

Matthew P. McAllister wrote: "Comic books can and have contributed positively to the discourse about AIDS: images that encourage true education, understanding and compassion can help cope with a biomedical condition which has more than a biomedical relevance" [1]. With this in mind, I combined a 23-narrator oral history and my personal memoir about an inpatient Chicago AIDS hospital unit in my book, *Taking Turns: Stories from HIV/AIDS Care Unit 371*. In doing so, I built upon the existing rich history of HIV/AIDS in comics, which this article will briefly describe. Although not a comprehensive review of the intersection of AIDS and comics, the book is a tour through influences that proved useful to me. In addition, in making my book, I faced a distinct ethical issue with regard to representing patient experiences with HIV/AIDS, and I describe here how I addressed it.

Introduction

Making comics came to me not as an artistic exploration, but as a coping method in a moment of need. Throughout the second half of the 1990s, I was working as a nurse on the dedicated inpatient HIV/AIDS care Unit 371 at (now Advocate) Illinois Masonic Medical Center on Chicago's North Side. Unit 371 opened in 1985 to exclusively care for the needs of patients and families impacted by HIV/AIDS. I was having difficulty processing the many challenges of our work—specifically, the death of nearly all of our patients despite our exhausting efforts to control their opportunistic infections. Writing in a journal about my work was not helping to relieve my distress. It felt exhausting to even try to write about the many complex stories of our work and my reactions to them. Another attempt at coping—painting images as memorials to my patients—was also not working. The images alone did not capture my experience. One day, almost by accident, I discovered making comics, or sequential narrative panels combining word and image. Much to my amazement, making comics was a comfortable, enjoyable, and effective method of professional and personal expression. I continued to make comics to process my experiences in <u>HIV/AIDS care</u> nursing.

Unit 371 closed in 2000 due to the reduced need for inpatient care of AIDS patients, thanks to the success of combination antiviral therapies. A few years later, I became

aware that the history of Unit 371 had not been publically recorded. I had been planning to create memoir comics about Unit 371, so it made sense that I would widen my scope beyond my own experiences to include those of my former colleagues and anyone closely associated with the unit who was available and willing to participate. I decided to conduct an oral history of this unique place and combine it with my comic memoirs. The result is my book, *Taking Turns: Stories from HIV/AIDS Care Unit 371* [2].

Before I began working on the book in earnest, I wondered about the appropriateness of using a medium often associated with humor to address AIDS. The enduring positive impact of Art Spiegelman's *Maus* [3], a graphic novel of an oral history account of the Holocaust, convinced me that thoughtfully made comics could bear the weight of great human tragedy. But would my comics be up to the task? Were there specific considerations to bear in mind when making comics about AIDS? I turned to the work of comic artists who had come before me and had grappled with similar issues to inform my project.

Representing AIDS in Comics

I was certainly not the first person to use comics to share stories from the AIDS crisis. By the time I began drawing the comics specifically intended for inclusion in my book in late 2014, AIDS comics were plentiful. They seemed to fall into three categories that reflected my creative and academic goals: health education, social and political activism, and testimony/remembrance [1, 4].

Health education. Comics have long been used for public education purposes. With respect to health care education in particular, comics can be very useful for communicating quickly and directly arcane and important information to a reader who might be under great stress. Comics have the advantage of generally being low cost and low tech and carry the ability to potentially transcend language and literacy barriers. (The cards found in airplane seat-back pockets describing procedures to follow in the event of an emergency are a great example of use of comics in critical crisis information messaging.) For these reasons, many community and public health groups have used comics as an educational tool to communicate, for example, how to avoid HIV transmission [4]. Many of these comics have been created by, and targeted to, specific age groups, behavioral risk groups, and racial minorities to meet unique needs of these communities [1, 4].

Social and political activism. Activist comics, created and published during the height of the AIDS crisis in the US and throughout the world, took several forms. Single- or limited-panel editorial comics addressing the personal, social, and political impact of the AIDS epidemic appeared in newspapers and magazines [5]. These works directly invoked the long history of political comics. Narrative comic anthologies, featuring the work of many well-known cartoonists, were edited and sold to raise funds for AIDS charities [6, 7].

Original works were often created specifically for these collections, and they serve as powerful historical documents bearing witness to societal attitudes about HIV/AIDS, anxieties about HIV transmission, and disparities in access to care that existed at the moments of their release. Multipanel serial narrative comics, created by members of the gay and lesbian community, were published in weekly gay and lesbian newspapers and magazines. These comics also addressed the AIDS crisis and sought to reflect and comment on current conditions in the gay community and potentially bring about social and political change.

One example of these serial narrative comics is *Wendel*, created by Howard Cruse. The goal of Cruse's comic strip was to "show what everyday gay life was like" (oral communication, January 2017). As the AIDS crisis overwhelmed the gay community during *Wendel*'s run, Cruse reports that he found himself feeling conflicted.

Every reality-based writer at the time struggled with this. Comics creators had a particularly difficult challenge addressing as serious a phenomenon as AIDS in comics, traditionally an environment largely devoted to humor.... I made several tries at doing a narrative, but felt that everything I came up with was trivializing the disease. This was something that people were dying horrible deaths from, I couldn't just make it a casual comic book plot device (oral communication, January 2017).

Concerned that, after nine years of the AIDS epidemic in the US, popular culture was still portraying all gay men as hovering at death's door (as exemplified by the fate met by Garry Trudeau's character Andy Lippincott in the nationally syndicated newspaper comic strip *Doonesbury*), Cruse portrayed his character Sawyer as rebounding from illness and rejoining the AIDS activism that was characteristic of real-world people who were dealing with AIDS at the time. "I wanted to represent the worried well," Cruse said. "People with HIV did get better, they had times in good health" (oral communication, January 2017). With this thought in mind, Cruse introduced the disease into his comics, not as a death sentence, but as a part of life, to serve an important narrative purpose (see figure 1). From Howard Cruse I learned that, for representing marginalized and <u>stigmatized communities</u>—in this case, both the gay community and the HIV community—narrative tools have power and, when used thoughtfully, should accurately reflect the community being represented.



Figure 1. Two panels from 1987 *Wendel* comic strip [8]. © 1987 by Howard Cruse. Reprinted by permission of Howard Cruse.

Testimony/remembrance. When I began to work on *Taking Turns*, I knew of four graphic novels and memoirs in which AIDS had a featured role in the story. Two of these were fictional accounts of serodiscordant (one partner HIV positive, one partner HIV negative) heterosexual couples: *Blue Pills: A Positive Love Story* by Frederik Peeters [9] and *Positive* by Tom Bouden [10]. Two others, *7 Miles a Second* [11] and *Pedro & Me: Friendship, Loss & What I Learned* [12] were nonfiction remembrance comics, what Timothy Murphy calls in the context of memorial writing about deceased persons with AIDS, "testimony" [13]. Murphy points out that testimony in the context of HIV/AIDS is actually not separate from activism.

Elegy, or testimony, as I prefer to call it, belongs to the continuum of moral and political conscience which fuels activism in the epidemic and has an important function in the protection of the individual. Such testimony also offers the opportunity for resisting the infantilizing of the dying and the dead which often occurs in the context of their health care [14].

The first of these works was a collaborative project. In *7 Miles a Second*, James Romberger illustrated the memoir of the late artist David Wojnarowicz. This graphic memoir bears witness to the physical and emotional trauma of life on the margins of society via Wojnarowicz's experience of living with AIDS in the early 1990s. *Pedro & Me*, by Judd Winick, tells the story of a friendship that started in fear of HIV contagion and ended in a deep understanding of the burden of disease and stigma. As readers, we bear witness to Winick's conversion from anxious roommate to understanding and loving friend. This graphic memoir thereby models a compassionate approach to people living with, and dying of, AIDS. All these books exemplify the power of graphic narrative to bear witness to suffering and, in doing so, perhaps have a role in creating positive social change.

One other testimonial comic that influenced and encouraged my work on *Taking Turns* is "Bearing Angry Witness" (see figure 2), a comic story by New York cartoonist Jennifer Camper that ran in gay and lesbian independent publications in the US in 1993 [15]. I came across it a few years into my work as an AIDS nurse and felt it best captured my experience with the epidemic as both a professional caregiver and member of the gay community. As Camper so beautifully illustrates, in times of crisis, the profound infuses what should be the mundane; everyday details of life become absurd reminders of great loss and pain. This was an important lesson I brought to my own work.



Figure 2. "AIDS: Bearing Angry Witness." © 1993 Jennifer Camper. Reprinted by permission of Jennifer Camper.

An Ethical Consideration Specific to Taking Turns

Despite all of the guidance I gleaned from comics focused on HIV/AIDS, I needed to resolve one area of ethical consideration specific to my book. As a nurse, I am bound by and committed to the confidentiality restraints of the Health Insurance Portability and Accountability Act (HIPAA), which protects individually identifiable health information

held by covered entities, such as health care providers [16]. And while I did not want to tell or presume to tell my patients' stories, as they are not mine to tell, I did need to touch on those stories in order to relate my experiences as a nurse on Unit 371. However, with the exception of one narrator/character in the book ("Roger"), my patients could neither be interviewed nor consent to their inclusion in the book because they no longer were alive. Despite changing names and avoiding other identifying features, I remained concerned that I might unwittingly reveal a patient's identity as I related the history of a specific unit in a specific hospital. Comics, of course, add a visual dimension, which can potentially increase the possibility of inadvertent identification if the avatar representing a patient too closely resembles an actual patient.

A main storyline in my book follows a character I called "Tim." In life, "Tim" had been involved in the arts, but not as a painter as I portray him. He and I had become friends, and he expressed an interest in collaborating with me on artistic projects. He consented to being photographed for a colleague's art project about AIDS care and expressed that he enjoyed this participation. By changing his name and his artistic medium that he had so loved in my book, I felt almost as though I were dishonoring "Tim's" memory or that he might think so were he alive. Needless to say, this notion bothered me a lot.

After much struggle, I resolved the issue with a compromise that worked for me. As I did with the two other featured characters in my book, "Stephen" and "Jane," I created "Tim" as a composite character, combining my patient and friend's story with another actual patient's creative endeavors, another's illness trajectory, another's back story, another's appearance, and yet another's circumstances of death. This approach not only resolved my concern about inadvertently disclosing patient identities but also allowed me to remember and honor many more of my patients while not dishonoring, I hope, the memory of any one of them.

Conclusion

I am grateful for the guidance and assurance I was able to gain from comic creators who came before me who told stories of HIV/AIDS for education, activism, and testimony. From them I learned that HIV/AIDS can effectively be represented in comic form and that it is best done with careful attention paid to the real and potential impact of the narrative on the communities and individuals being represented.

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MK Czerwiec, RN, MA, is a senior fellow at the George Washington School of Nursing Center for Health Policy and Media Engagement in Washington, DC, and artist-inresidence at Northwestern University Feinberg School of Medicine. She is the co-curator of the Graphic Medicine website.

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ABOUT THE CONTRIBUTORS

Theme Issue Editor

Taylor Olmsted, MD, is a pediatric hematology/oncology fellow at Texas Children's Hospital and Baylor College of Medicine in Houston. Her interests include benign hematology with attention to immune thrombocytopenia. In addition to scientific pursuits, she is interested in comic art and its role in medical ethics and humanities.

Contributors

Hannah R. Abrams is a second-year medical student at Baylor College of Medicine in Houston.

Rogelio Altisent, MD, PhD, is a general practitioner with the Research Group in Bioethics at the University of Zaragoza in Aragón, Spain. His professional interests include family medicine, bioethics, professionalism, education, teaching innovations, and clinical ethics committees.

Gary Ashwal, MA, is a health communication specialist and multimedia content producer based in Los Angeles and the co-founder of Booster Shot Media. He earned a master's degree in health communication from Emerson College and Tufts University School of Medicine and a BS in performance studies from Northwestern University.

Jason Bitterman, MD, is a resident in physical medicine and rehabilitation at Rutgers New Jersey Medical School/Kessler Institute for Rehabilitation in Newark, New Jersey. His medical comics are published at <u>www.bittermensch.com</u>.

MK Czerwiec, RN, MA, is a senior fellow at the George Washington School of Nursing Center for Health Policy and Media Engagement in Washington, DC, and artist-inresidence at Northwestern University Feinberg School of Medicine. She is the co-curator of the Graphic Medicine website.

Maria Teresa Delgado-Marroquín, MD, PhD, is an assistant professor of ethics at the University of Zaragoza Medical School in Aragón, Spain, where she also practices at Delicias Norte Health Center. She is trained as a bioethicist and general practitioner.

Jared Gardner, PhD, is professor of English at The Ohio State University in Columbus, Ohio. He is the author of three monographs, including *Projections: Comics and the History* *of 21st-Century Storytelling* (Stanford University Press, 2012), and he is editor of *Inks: The Journal of the Comics Studies Society.* He is currently working on a book, tentatively titled *Patient Time,* about graphic narrative, time, and illness.

Michael D. F. Goldenberg, MA, is a second-year medical student at Penn State College of Medicine in Hershey, Pennsylvania. He completed a master of arts degree in comparative literature at the Pennsylvania State University, with a thesis focusing on the use of comics in medical education and patient care.

Michael J. Green, MD, MS, is a physician and bioethicist at Penn State University's Milton S. Hershey Medical Center, where he is also the interim chair of the Department of Humanities, chair of the hospital ethics committee, and director of the Program in Bioethics. An innovator in the use of comics in medical education, he is part of the editorial collective for Pennsylvania State University Press's book series on graphic medicine, is guest editor of the Graphic Medicine section of the *Annals of Internal Medicine*, and teaches a course on comics and medicine to fourth-year medical students. He is a co-editor of the *Graphic Medicine Manifesto* (Pennsylvania State University Press, 2015).

Mónica Lalanda, MD, MSc, is an emergency medicine physician in Spain and holds master of science degrees in medical ethics and bioethics. She is also a comic artist.

Jeffrey Monk, MD, is a general pediatrician practicing in York, Pennsylvania. He attended Penn State College of Medicine and remained in Hershey, Pennsylvania, for his pediatrics residency at the Milton S. Hershey Medical Center Children's Hospital. He is a life-long fan of comics and graphic novels, and keeps a hoard of comic books in long-boxes under his bed because he may want to read them again someday.

Kimberly R. Myers, MA, PhD, is an associate professor of humanities and medicine at Penn State College of Medicine in Hershey, Pennsylvania. She has published in professional journals including *JAMA*, *British Medical Journal*, *Annals of Internal Medicine*, and *Academic Medicine* and lay periodicals including the *Atlantic* and the *Chronicle of Higher Education*. Dr. Myers is editor of three international, multidisciplinary books and coauthor of *Graphic Medicine Manifesto* (Pennsylvania State University Press, 2015).

Linda S. Raphael, MA, PhD, is the director of the program in medical humanities at the George Washington University School of Medicine in Washington, DC. She is the author of *Narrative Skepticism: Moral Agency and Representations of Consciousness in Fiction* (American University Press, 2001), *When Night Fell, an Anthology of Holocaust Stories* (Rutgers University Press, 1999), and articles on literature and on medicine and humanities.

Madden Rowell, MD, is a resident in primary care at Yale University School of Medicine in New Haven, Connecticut. She is a graduate of the George Washington University School of Medicine and Scripps College.

Susan M. Squier, PhD, is Brill Professor Emerita of English and women's, gender, and sexuality studies at Pennsylvania State University in University Park, Pennsylvania, and an Einstein Visiting Fellow at Freie Universität, Berlin, where she is a collaborator on the PathoGraphics Project. The co-author of *Graphic Medicine Manifesto* (Pennsylvania State University Press, 2015) and co-editor of the Graphic Medicine Book Series at the Pennsylvania State University Press, she is the author of *Liminal Lives: Imagining the Human at the Frontiers of Biomedicine* (Duke University Press, 2003) and *Epigenetic Landscapes: Drawings as Metaphor* (Duke University Press, 2017)

Alex Thomas, MD, is a pediatric allergist and immunologist based in Chicago and a cofounder of Booster Shot Media. In addition to his clinical practice, he is also a cartoonist and illustrator with more than 20 years' experience. He earned a BA in art theory and practice from Northwestern University and an MD from Rush Medical College and completed both his pediatrics residency and his allergy/immunology fellowship at the University of Wisconsin School of Medicine and Public Health.

Carol Tilley, PhD, is an associate professor in the School of Information Sciences at the University of Illinois at Urbana-Champaign. She studies the reception of and reading practices related to comics as well as the clinically based work of psychiatrist Fredric Wertham. A 2016 Eisner Awards judge and current president-elect of the Comics Studies Society, Tilley is a frequent speaker on comics history, comics in libraries, and graphic medicine.

Mark Tschaepe, PhD, is an assistant professor of philosophy at Prairie View A&M University in Prairie View, Texas, and an adjunct assistant professor at Baylor College of Medicine. He is also a board director for AIDS Foundation Houston, instructor of a course on diversity for the South African Medico-Legal Association, and a consultant for a medical information therapy project at the University of Namibia School of Medicine.

Megan Yu is a recent graduate of the University of Virginia and plans to attend medical school. She has interests in narrative medicine, health policy, neuroscience, and computational biology.