

## MEDICAL NARRATIVE

### Representing AIDS in Comics

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#### 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 [HIV/AIDS care](#) 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 [stigmatized communities](#)—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.

## **References**

1. McAllister M. Comic books and AIDS. *J Pop Cult.* 1992;26(2):22.
2. Czerwiec MK. *Taking Turns: Stories from HIV/AIDS Care Unit 371.* University Park, PA: Pennsylvania State University Press; 2017.
3. Spiegelman A. *The Complete Maus.* New York, NY: Pantheon; 1996.
4. Rifas L. AIDS educational comics. *Ref Serv Rev.* 1991;19(2):81-87.

5. Forman M, Horsey D, eds. *Cartooning AIDS around the World*. Dubuque, IA: Kendall Hunt; 1992.
6. Melia D, Gracey-Whitman L, eds. *Strip AIDS: A Charity Project for London Lighthouse*. London, England: Willyprods/Small Time Ink; 1987.
7. Robbins T, Sienkiewicz B, Triptow R. *Strip AIDS USA: A Collection of Cartoon Art to Benefit People with AIDS*. San Francisco, CA: Last Gasp; 1988.
8. Cruse H. *From Headrack to Claude*. North Adams, MA: Nifty Kitsch Press; 2009.
9. Peeters F. *Blue Pills: A Positive Love Story*. Boston, MA: Houghton Mifflin Harcourt; 2008.
10. Bouden T. *Positive*. Seattle, WA: Northwest Press; 2012.
11. Wojnarowicz D, Van Cook M, Romberger J. *7 Miles a Second*. Seattle, WA: Fantagraphics; 2013.
12. Winick J. *Pedro & Me: Friendship, Loss & What I Learned*. New York, NY: Square Fish; 2009.
13. Murphy TF. *Ethics in an Epidemic: AIDS, Morality, and Culture*. Berkeley, CA: University of California Press; 1994.
14. Murphy, 53.
15. Jennifer Camper website. <https://jennifercamper.com/about>. Accessed November 30, 2017.
16. Standards for privacy of individually identifiable health information; final rule. *Fed Regist*. 2000;65(250):82462-82829. Codified at 45 CFR sec 160, 164. <https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/administrative/privacyrule/prdecember2000all8parts.pdf>. Accessed November 30, 2017.

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