American Life Writing and the Medical Humanities

American Life Writing and the Medical Humanities: Writing Contagion

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About the Author

Samantha Allen Wright is an Assistant Professor of English at William Penn University. She earned her Ph.D. in English from Texas Christian University in 2018. Her dissertation, titled Reading and Writing Epidemics: Illness Narratives as Literature, won Addran College of Liberal Art's (at Texas Christian University) Outstanding Dissertation Award of 2019. Her research revolves around the medical humanities, disability studies, and American literature. Her research has been published in the *Lamar Journal of Humanities* in a special medical humanities edition. This is her first monograph.

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I decided to write a book about epidemic disease about 10 years ago, while reading for my master's thesis. Although I didn't know the exact topic, I knew I wanted to study life writing and epidemic illness. After a decade worth of research, schooling, and writing, I'm humbled to present my work to a wider audience. Of course, this book would not exist without the help and encouragement of my colleagues, former professors, family, and friends for imparting both their wisdom and confidence in me over the years. Although there are far too many people to name, I'm grateful to all of you for your help over the years.

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Introduction

Interdisciplinary Epidemics: Illness Narratives in American Literature, Disability Studies, and the Medical Humanities

Epidemic disease shaped American history. Christopher Columbus and the early European colonizers brought smallpox to the Americas, decimating the native population and forever changing the history of both continents. The Influenza epidemic of 1918 (often referred to as the Spanish flu) killed so many soldiers during World War I that many speculate the disease helped end the war. Polio led to many scientists competing for a vaccine, which ended the outbreaks, advanced medical science, and added to the patriotic high many Americans experienced post-World War II. Epidemics bring death, destruction, change, and innovation.

On some level, an epidemic led to my very own existence. My grandfather, who had been blinded in World War II, was recovering at a boarding house in his home state of Alabama when several fellow boarders contracted polio in the late 1940s. Scared of "surviving hell in the Pacific only to die in Birmingham," my grandfather called a war buddy in Des Moines, Iowa – a place he had never been before – and decided a reunion was in order. On his first night there, he met my grandmother. The fear of contracting polio led my grandfather to move halfway across the country and steered him toward a brand-new life. Although his reaction to potentially catching a devastating virus was extreme, my grandfather was hardly the only person who has gone to extreme measures to avoid contagion. Disease, apparently, is a great motivator.

Stories like mine – quick anecdotes about epidemics – survive long after the epidemics pass. In my own repertoire, I also have stories about my great-great-grandmother who died of the flu in 1918 or about my mother's friend who died of AIDS the year I was born. In some cases, such as polio, these stories are all we have left of the epidemics. These tales come up time and time again in vaccination debates, with the people who remember the disease sharing their stories, desperately trying to get those who have never seen polio to understand its severity. In other cases, we barely even have stories. Many historians worry that the Influenza epidemic

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of 1918 could be largely forgotten because so few records exist of the flu, which was overshadowed by the war both during the epidemic and in historical record.

Writing Contagion seeks to add to the body of scholarship about American epidemics by examining the stories from these periods. Many people, including both patients and caretakers, meticulously recorded details of each epidemic, hoping to stop the diseases, treat patients, or to simply be remembered. Some epidemics, like human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), have countless stories; whereas, the influenza pandemic of 1918 has far fewer. Yellow fever, which flourished in many American cities in the late 1800s, is mostly recorded through letters, diaries, and in newspapers; polio, on the other hand, produced decades of book-length memoirs. These texts – the recordings of various viruses – shaped the landscape of American literature and still continues to influence American life writing. However, despite the great contributions that illness writing has made to American literature, many literary scholars view these texts as too clinical, too sensational, or too simple notwithstanding the fact that illness memoirs became a popular and best-selling genre in the United States during the mid-twentieth century and remain popular today. Earlier writings have similar importance; during the yellow fever outbreaks, women and people of color wrote about the disease in letters and in newspapers, allowing traditionally silenced groups to have a voice. At other times, illness writing can be seen responding to literary movements, such as modernism. And early polio memoirs started the genre of illness memoirs. *Writing Contagion* traces the history of illness writing in American literature and argues for the importance of illness narratives in American literature, history, and medicine.

My aim here is not to only focus on the historical importance of illness writing as a genre, but to imagine how illness writing can change the future too. *Writing Contagion* also examines how illness life writing can potentially unite two important fields: the medical humanities and disability studies. The medical humanities is an emerging field, which uses writing – as well as art, dance, and other forms of expression – about illness, health, and the body to examine medicine and healthcare. Illness narratives, a genre first described in-depth in 1988 by psychiatrist and sociologist Arthur Kleinman in *The Illness Narratives: Suffering, Healing, and the Human Condition*, are an integral part of this highly interdisciplinary field; healthcare providers read and listen to illness narratives as a way to better understand patients and to improve patient care, as well as to look at the issues of implicit bias within medical care and research. Although one of the main focuses of the medical humanities is to improve patient–provider relationships, in recent years, scholars have pushed for the critical medical humanities, which according to William Viney, Felicity Callard, and Angela Woods (2015), focuses on:

> (i) a widening of the sites and scales of "the medical" beyond the primal scene of the clinical encounter; (ii) greater attention not simply to the context and experience of health and illness, but to their constitution at multiple levels; (iii) closer engagement with critical theory, queer and disability studies, activist politics and other allied fields; (iv) recognition that the arts, humanities and

> social sciences are best viewed not as in service or in opposition to the clinical and life sciences, but as productively entangled with a "biomedical culture"; and, following on from this, (v) robust commitment to new forms of interdisciplinary and cross-sector collaboration. (p. 2)

The goals that Viney, Callard, and Woods state are quite ambitious, but clearly aim to develop the medical humanities into an interdisciplinary field which thoroughly investigates how conceptions of the body, illness, and medicine are affected and affect many aspects of both our daily lives and our society. Their focus on engaging with other "allied" fields, such as disability studies is an important focus, but this goal has yet to be realized. Disability studies certainly is an ally to the medical humanities; disability studies focuses on improving the lives of those with long-term illness and disabilities by both advocating for disability rights, questioning the definitions and conceptions of "normal" and "disability," and seeking to interact with other disciplinary fields. However, despite their similar focus and the fact that many scholars have sought out increased interdisciplinary connections in both fields, the medical humanities and disability studies still have relatively little crossover. *Writing Contagion* seeks to bridge this gap and contribute to the development of the critical medical humanities by exploring illness narratives as a genre in American literature, paying close attention to the intersections of disability studies and the medical humanities. Focusing mainly on book-length narratives of illness and disability, my project traces the development and lineage of the illness narrative from early American nonfiction writing, such as Puritan redemption narratives, to literary modernism and to contemporary memoir. I argue illness narratives are intensely interdisciplinary; to understand both the importance and influence of this genre within American literature, illness narratives need to be read through both literary and disability studies frameworks to challenge ableist assumptions and demonstrate how illness narratives are of both historical and literary importance in twentieth- and twenty-first-century America. To examine the development of illness narratives as a genre in American literature, I examine a variety of texts including Katherine Anne Porter's *Pale Horse, Pale Rider* (1939), Bentz Plagemann's *My Place to Stand* (1949), Peg Kehret's *Small Steps: The Year I Got Polio* (1996), Arthur Ashe and Arnold Rampersad's *Days of Grace: A Memoir* (1993), and Richard Preston's *The Hot Zone: The Terrifying True Story of the Origins of the Ebola Virus* (1999). To substantiate my argument of these books' importance, I consider these works in conversation with critical race theory and Crip theory, as these books narrativize experiences of illness and disability intertwined with multicultural and politicized contexts that draw enlightening parallels to experiences of sexuality, racial identity formation, contemporary politics, and social justice.

The History and Past Lives of Illness Life Writing

Although many historians have traced how epidemic disease has shaped United States history, few literary scholars have done the same. Illness narratives are a complicated genre; despite illness's commonality, few writers throughout American history have recorded illness narratives in detail until the mid-twentieth century. Although the illness narratives that do exist are frequently used in medical education or by medical professionals in clinical settings, illness narratives have a long and under-researched history within American literature. These narratives are closely related to other forms of American life writing (like autobiography, biography, letters, diaries, etc.). Since illness narratives span so many different genres, these texts need to be read through multiple critical lenses. Memoir is an increasingly popular genre in the United States today, with memoirs frequently appearing on best-selling lists.[1] From 2004 to 2008, three types of memoirs which are often about or include illness or disability, personal, childhood, and parental memoirs, increased 400% in sales (Yagoda, 2010, p. 7). In fact, some of the best-selling memoirs in the United States were about illness, such as Terri Cheney's 2009 *Manic: A Memoir* (bipolar disorder), Paul Kalanithi's 2019 *When Breath Becomes Air* (lung cancer), and Nina Riggs's 2017 *The Bright Hour: A Memoir of Living* (breast cancer). There is clearly a market for illness stories today, but the genre has not always been as popular as fiction or as other forms of life writing.

The history of American life writing reveals how illness narratives developed and shaped American literature. The memoir boom of the late twentieth and early twenty-first centuries often makes it seem as if memoir is a relatively new genre, but Americans have penned their stories for centuries. Although the majority of this history is outside the scope of my project, a cursory examination shows that memoirs and other forms of life writing have always been a popular topic in American literature, although life writing specifically about illness or disability remained rare until the twentieth century. Ben Yagoda writes in *Memoir: A History* (2010):

> New England Puritans wrote personal narratives from the get-go, because, unlike their counterparts across the Atlantic, they were required as a condition for church membership to give an account of their experience of grace. (p. 50)

Requiring these spiritual narratives meant that many churchgoers wrote these narratives for their churches. Yagoda argues spiritual narratives were so popular and significant in American literature that their influence remains today:

> While the spiritual autobiographies themselves were mostly bland and predictable, they had a long-lasting impact. If you look closely enough, you can find their influence in the majority of American memoirs … with traces in such diverse works as *The Autobiography of Malcolm X*, Jimmy Carter's *Living Faith*, Augusten Burrough's

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[1] My project primarily focuses on memoir. However, other forms of life writing such as autobiography, biography, letters, diaries, etc. share some of the same history. Even though memoir is a distinct category of life writing, much of the history provided here is true for various other forms of life writing.

> *Running with Scissors*, and James Frey's *A Million Little Pieces*: books that follow an account of the author's wayward past (and the more wayward, the better), his or her discovery of some sort of secular or sacred light, and then, finally, sweet redemption. (2010, p. 52)

Spiritual memoirs were followed by captivity and salve narratives, and from 1800 to 1850, many other life writing topics gained traction:

> […] Clergy/Religious or Criminal/Deviant accounted for 57 percent of such books … By the first decade of the twentieth century, Clergy/Religious was still the most common category at 22.7 percent, but the Criminal/Deviant was down to 4.4 percent, and other categories made strong showings. (Yagoda, 2010, p. 120)

"Military life," "politician," "business," and "frontier life" were also popular topics for memoirs (2010, p. 120). The twentieth century brought many changes to life writing, including the formation of illness narratives as a genre in the mid-twentieth century. However, the end of the twentieth century and beginning of the twenty-first century changed the history of the memoir in America dramatically. Despite the fact that memoirs had always been a popular genre in American literature, sometime around the turn of the century America experienced a "memoir boom."[2] In her book, *Boom!: Manufacturing Memoir for the Popular Audience* (2013), Julie Rak defines the memoir boom as the period "when the production and public visibility of American and British memoirs by celebrities and by relatively unknown people sharply increased," making memoirs far more popular[3] among readers (p. 3). Since more people were reading memoirs, the number of memoirs published increased significantly.

Although America has a long history of memoirs, illness narratives were few and far between (although, as I explore here, immensely important) until the second half of the twentieth century. Illness, which was often considered gauche or inappropriate in American society before the twentieth century, slowly became a more acceptable topic, partially due to polio memoirs, which forever changed how Americans wrote about illness and disability. Today, illness narratives are widely read and attract considerable public interest – a drastic change from past years. In *Reconstructing Illness: Studies in Pathography* (1999),[4] Anne Hunsaker Hawkins posts that illness narrative receive so much attention today because:

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[2] While Julie Rak places the memoir boom as "a period roughly spanning the first decade of the twenty-first century," others place the start date in the 1990s. Regardless of exact years, memoirs have become increasingly popular over the past 30 or so years.

[3] I use the term "popular" here to reflect the increase in number of published memoirs.

[4] Hawkins (1999) defines pathography as "a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death" (p. 1). Pathographies and illness narratives do have some slight differences, but by Hawkins's definition, pathographies and illness narratives are more or less the same.

> They provide a "good read." Pathographies are compelling because they describe dramatic human experience of real crisis: they appeal to us because they give shape to our deepest hopes and fears about such crises, and in so doing, they often draw upon more profound archetypal dimensions of human experience. (p. 31)

Today's illness memoirs not only provide a "good read," but also contain medical advice, inspiration, and support for readers. However, the illness narrative genre is very diverse; many illness narratives have various forms, topics, and goals. Some memoirs focus solely on illness, while others explore the lived experience of illness through discussions of religion or family. Many memoirs choose to offer medical advice to their readers (such as alternative medicine practices), while others write simply because their illness makes for a captivating story. Most writers attempt to inspire and encourage readers through their stories, but often times, the writer's goals depend on their specific illness or disability. For example, polio memoir writers had little medical advice to offer,[5] but instead choose to present a message of hope (*if I can survive extreme hardship, you can too*) or try to help their readers understand the difficulties of illness and disability (*this is what life is like with polio and/or significant disability*).

Although illness narrative can vary quite a bit, Arthur Frank argues in *The Wounded Storyteller: Body, Illness, and Ethics* (2013), most illness narrative fit within three narrative types: the chaos narrative, the restitution narrative, and the quest narrative, which Frank argues is most popular form of published illness narratives (p. 115). Many illness memoirs fit firmly into the last category, the quest narrative, which Frank defines as narratives which "meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience" (2013, p. 115). Chaos narratives are rare and exceedingly difficult to narrate, excluding most illness narratives from this genre, although some illness narratives, particularly modernist or other experimental texts, do fall into the chaos narrative category. The last type, the restitution narrative, as Frank describes, "has the basic storyline: 'Yesterday, I was healthy, today I'm sick, but tomorrow I'll be healthy again'" (2013, p. 77). Since most illness stories fit into one of these types, we can easily trace the similarities between illness narrative and other forms of life writing, which often use the same narrative structures.

For example, examining illness narratives as quest links today's illness narratives to the history of American life writing. Frank's quest narrative, despite its seeming similarities with *The Odyssey* or other famous quest or hero's journey stories, actually has more in common with eighteenth- and nineteenth-century American life writing, such as conversation narratives. Anne Hawkins (1999) writes:

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[5] Polio memoirs, unlike memoirs of other conditions, rarely give medical advice because other than supportive care during the acute phase and physical therapy/rehabilitation afterward, there are no other treatments for polio.

> our contemporary pathographies have their closer counterparts in a kind of literature that at first must seem radically different: autobiographies describing religious conversion. Indeed, it almost seems as though pathography has replaced the conversion autobiography of earlier, more religious cultures. (p. 31)

In Frank's quest narrative, the author uses illness as a journey and eventually is rebirthed as a new person who has learned something valuable about life, and these lessons are reflected on and shared (frequently for pedagogical purposes) in the text. This quest narrative, which Frank uses to describe illness narratives, could also describe conversation narratives, which have remarkable similarities in terms of plot and structure. As Hawkins argues, the writer's change throughout the story is the largest commonality linking today's illness narratives with eighteenth- and nineteenth-century conversation narratives:

> The most striking similarity between pathographies and autobiographies of conversion is that both, with their focus on extraordinary or traumatic experience, give special prominence to myths about personal change. The myth of rebirth, which is central to autobiographies about conversion is also the organizing construct for a good many pathographies. It turns on the belief that one can undergo a process of transformation so profound as to constitute a kind of death to the "old self" and rebirth to a new and very different self. (1999, p. 33)

Clearly, the journey, or as Frank writes, the quest narrative, links today's illness narratives to earlier religious narratives, proving that illness narratives are linked to earlier forms of American life writing. By tracing the history of illness narratives in conjunction with other related elements in American literary history, it becomes clear that illness narratives are not a new genre written for a niche market, but rather a genre with a long history within American literature. *Writing Contagion* explores this history in order to demonstrate that illness narratives, even if they are rare at times, have continually evolved and changed with American literature, and at times, actually shaped America's literary history forever.

The Future of Illness Narratives

By recognizing the literary and historical importance of illness narratives, we also have to consider the role that this genre will play in the future. Illness narratives – particularly illness memoirs – are an established and popular genre in the twenty-first century and have a wide popular readership. This readership and interest in reading illness stories works to destigmatize illness, advocate for better treatments, share advice, and inspiration to others. Since illness narratives have received this kind of prominence, *Writing Contagion* explores how reading illness narratives through multiple theoretical lenses will help move the genre into the future. In particular, I focus on how illness narratives have the potential to unite two particular fields, disability studies and the medical humanities. At first glance, the medical humanities and disability studies seemingly share many common goals. Both fields are becoming increasingly important in the twenty-first century, and both advocate for better medical and social treatment of those with illnesses, disabilities, and/or physical or intellectual differences. In recent years, scholars have argued that the medical humanities can be divided into two waves. The first wave focused largely on blending medicine with the humanities, the social sciences, and the arts in order to train healthcare professionals to become more compassionate, empathic, and ethical in their practice. These early goals are interdisciplinary by design, intending to benefit patients and improve healthcare. However, more recently, the medical humanities has moved into the critical humanities, a second wave which seeks to expand past the earlier goals of the field. Anne Whitehead and Angela Woods argue in their introduction to *The Edinburgh Companion to the Critical Medical Humanities* (2016a), that the critical medical humanities opens up:

> possibilities for the medical humanities to operate in radically different areas of critical consideration, to address difficult, more theoretically charged questions, and to claim a role much less benign than that of the supportive friend. How might the bodies of doctors and patients be marked in terms of race, class, gender, ability and disability, and with what effects? What else, we might ask, is in the room, and with what forms or modes of agency might it be associated? (p. 2)

This move past focusing mainly on patient–practitioner interactions and medical education (which is still a goal of the critical medical humanities) aligns more closely with the work many scholars do in disability studies. Disability studies, like the medical humanities, is highly interdisciplinary and draws from many different fields – such as history, literature, sociology, and political science – to examine how disability is a socially constructed minority identity and to enhance the lives of those with disabilities through activism and awareness. Unlike the medical humanities, disability studies originates from the social sciences, but eventually grew to incorporate humanities scholars. Literature scholars, for example, added to disability studies at first by examining the role disability played in literature throughout the years. More recently, disability studies has, in addition to activism, sought to interrogate questions of normality, the body, and how society perceives disability. Geoffrey Reaume (2014) argues that critical disability studies scholars:

> view disability as both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world, and as a social and political definition based on societal power relations. Emerging from the activism of disabled people in the 1970s, this area of study involves both academics and activists representing multiple disciplines and perspectives. It challenges approaches that pathologize physical, mental and sensory difference as being in need of correction, and instead advocates for both