

Examining Agency in Contemporary Young Adult Illness Narratives

Although we do not know the precise reason young adult (YA) shelves have been infected, Green's (2012) *The Fault in Our Stars* can be pinpointed as the origin of the growing genre of "sick lit" (Carey, 2013). We borrow the term *illness narratives* from the medical humanities, an interdisciplinary field that merges medicine and the humanities and is relatively unexplored in the secondary English classroom. The three *fictional* YA illness narratives in this article feature adolescents who exhibit agency as they voice and act on self-made decisions (Agency, 2014) and offer teachers and students opportunities to engage in a rhetorical analysis of agency within novels that debunk traditional presentations of adolescents with physical or mental illness as powerless.

We define the term *agency* as an adolescent's ability to gain knowledge or speak or act in a way that allows the young person to maintain a sense of humanity while occupying simultaneously what can be the dehumanizing role of patient. McGovern (*n.d.*) commented on how today's youth understand peers with disabilities: "Today's typically-developing kids are more aware of people with disabilities than their parents were, but they don't necessarily know them any better." Whereas we acknowledge there are various contexts in which adolescents with and without physical or mental illness exist within schools, we believe many students with mental or physical illness reside in the margins of today's classrooms. YA illness narratives present a counter-narrative to traditional depictions of mental and physical illness because they provide a voice to adolescent patients

who are not often heard or validated. Smagorinsky (2014) described mental illness as a "critical area of multicultural education" (p. 15), and while the characters we present here have mental and physical illness, we agree that opening students' perspectives to adolescents' experiences—both similar to and different from their own—can have powerful effects. In their presentations of adolescents who are more than ill bodies and minds, Shusterman's (2015) *Challenger Deep*, Thomas's (2015) *Because You'll Never Meet Me*, and Toten's (2015) *The Unlikely Hero of Room 13B* showcase adolescents with agency, thus allowing students—both with and without a diagnosis—to gain empathy through discussions and activities that help them think critically about agency, both in YA illness narratives and in their lives.

Approaching our work through a critical literacy lens allowed us to emphasize the importance of having students interrogate the voices given or not given agency in these texts (Stevens & Bean, 2007). Analyzing why particular voices are foregrounded or not in YA illness narratives relates directly to the aims of critical literacy, which is "focused on the uses of literacy for social justice in marginalized and disenfranchised communities" (Luke, 2012, p. 5). Curwood (2013) suggested that YA literature that features "characters with disabilities . . . offers teachers the powerful opportunity to build students' critical literacy skills" (p. 18). As we share in our implications section, the YA illness narratives explored here provide opportunities for students to engage in Lewison, Flint, and Van Sluys's (2002) four elements of critical

literacy: disrupting the commonplace, interrogating multiple viewpoints, focusing on sociopolitical issues, and taking action and promoting social justice.

Review of the Literature

Our work is informed by the literature on the medical humanities, illness narratives, and agency. As a broad field bringing together medical sciences and

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the humanities (Medical Humanities, 2004), the medical humanities has created a space for those experiencing illness to share their experiences via illness narratives. Resisting the dehumanization of the medical sciences (Crawford, Brown, Baker, Tischler, & Abrams, 2015), these counter-narratives allow patients to gain agency

over their stories and, in some part, their illnesses. By shifting the language surrounding illness from sterile pathology to a rhetoric of agency that focuses on the stories and experiences of the whole person, illness narratives seek to shift power back to patients within the medical-industrial complex (Charon, 2006; Couser, 1997; Garden, 2015; Rinaldi, 1996).

The Medical Humanities

The medical humanities is an interdisciplinary field defined as “the study of the intersection of medicine and humanistic disciplines such as philosophy, religion, literature, and the fine and performing arts” (Medical Humanities, 2004). Greaves and Evans (2000) cited two aims for the medical humanities:

The first is concerned with complementing medical science and technology through the contrasting perspective of the arts and humanities, but without either side impinging on the other. The second aims to refocus the whole of medicine in relation to an understanding of what it is to be fully human; the reuniting of technical and humanistic knowledge and practice is central to this enterprise. (p. 1)

As it resists the idea of the marginalized patient (Garden, 2015), the medical humanities focuses on humanizing patients and seeing them as people who

are not defined solely by their diagnosis (Crawford et al., 2015).

Illness Narratives

Illness narratives, or “writing[s] about the episode of one’s illness” (Couser, 1997, p. 6), epitomize the medical humanities. We might say that Virginia Woolf’s (1930/2002) illness narrative, *On Being Ill*—in its lamentations about the lack of language about the body and its assertions that those who are ill are able to appreciate more acutely life’s moments—was the precursor to today’s illness narratives. Contemporary scholars have emphasized the move away from the depersonalization of patients (Hawkins, 1999) and toward acknowledgment of patients’ voices in their care and the need for doctors to listen to patients’ voices (Charon, 2006; Garden, 2015; Rinaldi, 1996). What health care professionals can gain from interpreting illness narratives is powerful (Charon, 2006; Kleinman, 1988) in that illness narratives provide spaces for patients to provide counter-narratives that “help us understand what it means to be some body” (Couser, 1997, p. 295). Kleinman (1988) explained that a clinician who knows a patient’s story will be less likely to think of therapy for that person in a way that dehumanizes the patient and will be energized to care for the patient whom the clinician now identifies as a “moral agent” (p. 237). Those who write or have their illness narratives exposed become *people* rather than *patients* with a diagnosis.

Agency

As Defossez (2016) wrote, “There has been a surge of interest in, and respect for, ‘patient agency’ in public and professional discourses of health and medicine” (p. 2). *Agency* is a complex term with which rhetoricians have grappled for decades (Defossez, 2016).

Popular in the late twentieth century, George Engle’s idea of the biopsychosocial model of medical care in which “the doctor is working on a human, not merely a diseased body” (Stone, 1997, p. 204) seems particularly relevant to our discussion of agency because of its focus on the *human*. *Agency* has connections to patient control (Defossez, 2016; Stone, 1997), and we acknowledge scholars’ ideas about whether patients can truly have agency. Exposing the ironies of three ways of examining patient agency (i.e., agency as the capacity to know, agency as the capacity to prevent,

and agency as the capacity to decide), Defossez (2016) wrote, “While the rhetorics of patient agency persuade us that we have ultimate control and responsibility over our bodies and health, at some point in our lives, the ultimate uncontrollability of our bodies will be made apparent to us” (p. 16). Whereas healthcare professionals may view agency in terms of compliance and transmitting knowledge, individuals with illnesses can develop knowledge in the context of what can be complicated and emotional medical journeys (Hunter, Franken, & Balmer, 2015). The rhetoric around patient knowledge holds both a resistance to the stance of patient-as-passive-individual (Defossez, 2016) and a recognition of medical professionals’ power over patients even while giving appearances of patient agency.

Selection of Texts

Before deciding upon our three focal texts, we read several novels that fit within the current micro-trend of “sick lit”: Vizzini’s (2006) *It’s Kind of a Funny Story*, Andrews’s (2012) *Me and Earl and the Dying Girl*, Green’s (2012) *The Fault in Our Stars*, Haydu’s (2013) *OCD Love Story*, Scelsa’s (2015) *Fans of the Impossible Life*, Shusterman’s (2015) *Challenger Deep*, Thomas’s (2015) *Because You’ll Never Meet Me*, Toten’s (2015) *The Unlikely Hero of Room 13B*, and Yoon’s (2015) *Everything, Everything*.

We wanted selection criteria that moved beyond the fact that these texts are popular with secondary students and are featured frequently on bookstore shelves and recommended reading lists. Books had to exemplify fictional illness narratives and provide students a lens into adolescents with physical or mental illnesses who exhibit agency. Because we also wanted to share with students books that experts deem quality texts, we decided to limit our texts to award-winning books published within a single year. With this in mind, we selected books published in the United States in 2015 that either won or were nominated for a prominent award.

Based on our criteria, we identified three focal texts: Shusterman’s (2015) *Challenger Deep* was awarded the 2015 National Book Award for Young People’s Literature and was named to the 2016 Library Services Association’s Top Ten Best Fiction for Young

Adults list; Thomas’s (2015) *Because You’ll Never Meet Me* was a finalist for the 2016 William C. Morris Debut Award; and Toten’s (2015) *The Unlikely Hero of Room 13B* won the 2016 Schneider Family Book Award and the 2014 Ruth and Sylvia Schwartz Children’s Book Award.

We originally identified two more books that did not make the final cut for our selection criteria after our initial reading. Although it reveals one of the main character’s struggles with depression, *Fans of the Impossible Life* (Scelsa, 2015) did not earn a prominent award. And *Everything, Everything* (Yoon, 2015), a text that includes a diverse female protagonist (a feature we admired in the text), has an ending that prevents it from fitting into the category of an illness narrative. Though we acknowledge the lack of diversity in terms of protagonists and representations of diverse socioeconomic status and intersectional identities within the “sick lit” genre (something we recommend discussing with students in the Implications section), our focal texts were selected because they provide contemporary, fictional accounts of adolescents with physical and mental illnesses who exhibit agency. More information about the three focal texts, including how agency is explored within these texts, is shared in Table 1.

Methods

We drew on critical discourse analysis (CDA) as a tool for identifying ideologies of agency (Gee, 2014). CDA examines not only the use of language in text and the situated meaning of language but also how language is connected with social practices. According to Gee, critical approaches to discourse analysis “treat social practices, not just in terms of social relationships, but, also, in terms of their implications for things like status, solidarity, the distribution of social goods, and power” (p. 87). CDA underscores that language

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Table 1. Texts that feature adolescents' illnesses

Author and Title	Type of Illness	Brief Synopsis	Elements of Agency
Neal Shusterman's (2015) <i>Challenger Deep</i>	schizophrenia	Caden, a teenager with schizophrenia, spends time in a mental health facility.	Caden's verbalization of illness through first-person narrative, protesting doctors' prescriptions, acute awareness of others' perceptions of him, his artwork
Leah Thomas's (2015) <i>Because You'll Never Meet Me</i>	electricity allergy, heart condition	Two boys—Ollie, who has an electricity allergy, and Moritz, who has a pacemaker—develop a deep bond via writing letters.	Moritz and Ollie's letters to each other, Moritz and Ollie's medical knowledge, Ollie's relationship with Liz
Teresa Toten's (2013) <i>The Unlikely Hero of Room 13B</i>	obsessive-compulsive disorder	Adam, the son of divorcees, contemplates what it means to save oneself as part of a group for teenagers with obsessive-compulsive disorder.	Characters' relationships in group, Adam's infatuation with Robyn, Adam's superhero identity as Batman

both represents and reinforces power. One perspective within discourse analysis is the agent-patient distinction, or the distinction between “what is done *by* a person and what is done *to* a person” (Wood & Kroger, 2000). The YA illness narratives we have selected are particularly suited to this type of analysis because of what they reveal about patients with agency.

Using Glenn's (2008) and Curwood's (2013) critical discourse analysis of young adult novels as guides, we engaged in three levels of analysis. First, we read each book, focusing on the general plot, themes, and character development and whether the novels fit our criteria as illness narratives. Next, we both read all three books a second time, each of us coding separately for emergent themes related to agency. We both highlighted key passages in the novels and compiled these passages into lists based on potential themes. We then discussed, combined, and eliminated individual themes from our independent lists in order to come to a consensus on emergent themes based on relevance and prevalence across texts. A third and final reading was focused on finding textual evidence to support the identified themes.

Examining Patient Agency in Three Focal Texts

The adolescents in the focal texts we selected are not defined by their illness. When faced with dire deci-

sions, they make adult choices, and they gain agency as they take control over their particular circumstances. Several themes emerged from a rhetorical analysis of how agency functioned in YA texts: a clear personal articulation of illness, the positioning of patients as medical experts, and a privileging of illness management over romantic relationships.

Articulation of Illness

Across all three focal texts, adolescents living with illness demonstrate agency by describing their illness on their terms. In her piece “Welcome to Cancerland,” Ehrenreich (2001) dismissed the overwhelmingly hopeful nature of cancer narratives and the pink-ribboned bears contained within. Noting that positivity might have a place in the cancer narrative, she commented, “Cheerfulness is more or less mandatory, dissent a kind of treason.” What became clear as we explored the focal texts was the brutal honesty with which characters discuss their illnesses, even when these descriptions are not positive. All four characters struggle, on some level, with sharing the details of their complicated lives, but all eventually share these inner worlds with their peers, doctors, and the world at large.

One of the struggles Adam faces in *The Unlikely Hero of Room 13B* is his weekly homework for his therapist. Each week he is supposed to keep a record of things he knows, as well as how his medications

are working. He writes four lists in the novel, and the reader follows his struggle—both to actually complete each list and to complete each list honestly. It is not until the last list, at the climax of the novel, that Adam recognizes the importance of this assignment and completes the list without cheating. Adam is candid with *himself* in the final list so that his therapist can truly help him. He accepts his need for medicine, as evidenced in these lines:

Meds: Ativan (I need a new prescription)
Anafranil 25 mg 3 x per day (need a new script there too)
(p. 240).

In order for the treatments to work, Adam has to understand his agency to use tools available to him (including his medications, therapist, and support group) to manage his condition. His narrative exhibits how this process is neither easy nor immediate, but also how he comes to fully acknowledge his role in “getting fixed.”

Because You’ll Never Meet Me is an epistolary novel told through the letters of two boys with two different illnesses living on two different continents. The author’s choice of style here is an important element in giving her characters voice to articulate their illnesses. These letters collectively become illness narratives as both boys pen their stories to each other, a point that Ollie addresses directly in his first letter to Moritz: “So these letters will be my autobiography” (p. 10). He explains to Moritz that these letters are not just friendly social conversations, but also a way for him to share his story with someone else who has experienced similar hardships.

In Ollie’s first letter, he is careful to divulge the right details in the right order at the right time to craft the story he wants to tell. When he slips and hints at a detail that was out of place, he catches himself by saying, “I’ll tell you about that later because Mom says that good autobiographies are linear, like life. Like, I should tell you about being a toddler before I talk about being a kid” (p. 10). Throughout all of their letters, both Ollie and Moritz describe their letters as each other’s “story,” though Ollie is initially more forthcoming in providing the details of his circumstances and emotions. Moritz does eventually begin to trust Ollie, writing, “Your honesty about your suffering—your confounded honesty!—has at last given me cause to share my own trials with you” (p. 246).

It is this trust and honesty through the written word that finally allow Ollie and Moritz to put together the puzzle of their lives, their illnesses, and how these intertwine. This is the discovery that gives both boys a full understanding about the causes of their conditions, giving them agency to take action.

In particular, both boys experience social isolation as a result of their respective conditions. Moritz, a German boy born without eyes, is particular about the language he uses to describe his physicality. In his first letter to Ollie, Moritz writes, “I was born without eyes. Do not ask if I am blind. I have never been blind. But I was born with no eyeballs in my sockets” (Thomas, 2015,

p. 26). However, it is Moritz’s descriptions of how he experiences the world and his articulation of his assets that give him power. For instance, he possesses a stellar sense of hearing: “I see with my ears. My brain uses sounds waves to determine the shapes of objects and barriers in my vicinity” (p. 28). He also shares his keen intellect with Ollie, but acknowledges the weakness of his heart and need for a pacemaker: “Of greater concern to me is the chronic weakness of my heart. But that is a story best left untold. Leave it be. Needling won’t reveal it” (p. 29). Here, Moritz expresses frustration with the ways in which he is understood by his peers and teachers, particularly when they have essentialized him to his physical features: “In my absence, there’d been an assembly about bullying ‘disabled’ students. In my absence, I’d become a label” (p. 99). Through writing to Ollie and crafting his own narrative as he sees it, Moritz demonstrates agency, debunking misconceptions about his abilities while also acknowledging the social isolation he feels in a world that treats him differently.

In *Challenger Deep*, Caden draws abstract representations of the world inside of his head. While the other novels we studied use only language to communicate unique descriptions of illness, Caden’s story

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uses the powerful combination of extended metaphors (e.g., serving the captain of the ship heading to the Mariana Trench) and chaotic images to add layers of meaning to the confusion of emergent schizophrenia. Here, Caden not only normalizes the complexities of a patient's brain, he also gains agency through making visible what is often not: his schizophrenia. Though these drawings ultimately help the reader see the

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invisible, their primary purpose is for Caden to make visible his own thoughts and better understand himself. In one scene, he writes, "These images have to mean something, don't they? Why else would they be so intense? Why would that silent voice inside be so adamant about getting them out?" (pp. 53–54). Caden's visual displays of what is happening in his mind permit him to articulate his illness on his terms and in his media, providing him agency.

Patients as Medical Experts

Parents and teachers generally serve in positions of power in adolescents' lives. Doctors and other healthcare professionals can easily become another rung on the power ladder. In our focal YA illness narratives, however, adolescents who are ill become medical experts. We use the term *expert* here not to mean these adolescents are able to alter the course of their treatment or illnesses, but rather to mean that they gain a voice. The ways in which these characters critically consume medical literature or advice allow them to attain agency. This information consumption aligns with contemporary scholarship about patients accumulating medical knowledge via technology; Danholt, Piras, Storni and Zanutto (2013) name this tech-savvy patient *Patient 2.0*. Adolescents in the focal texts prove that the modern patient is knowledgeable about his or her medical care, even to the point of being able to play with medical professionals, and they use language to position themselves powerfully over medical professionals.

In their letters to each other in *Because You'll Never Meet Me*, Ollie and Moritz share medical knowledge with each other using technical medical jargon.

Both boys have spent a great deal of time alone and possess curious intellects, so their time spent with doctors sparks an interest in why their bodies are the way they are. Early in the novel, Ollie corrects Moritz's medical language and explains how he knows so much about the human body:

"Oh, and the name of your lower-left heart chamber is actually your left ventricle, or your *ventriculus cordis sinister*" (p. 21). *Because You'll Never Meet Me* is unique among the three focal novels in this study because Ollie and Moritz, through their collective sharing of their narratives and deductive reasoning, come to understand a mystery about their conditions that has been deliberately withheld from them by a man whom they discover is their mutual doctor: Dr. Auburn Stache/*Rostschnurrbart*. In this case, both the boys' parents and medical professionals deliberately withheld information about their medical pasts, and the boys learn new information about their conditions through their research and knowledge.

Challenger Deep's Caden is very observant of his surroundings when he is placed in a mental facility, and he is able, at times, to use his observational knowledge to subvert doctors' orders. Even though it is not necessarily to his benefit, we understand Caden's critique of the medical-industrial complex's concern with controlling his negative behaviors at the expense of his ability to feel emotions. Near the end of the novel, Caden has had enough of being treated as an experiment by his doctors and yells, "Adjust my medications, adjust my medications, that's all you ever want to do is adjust my medications!" (p. 248). He goes on to explain to his doctor that "[anger is] real, isn't it? It's *normal*, isn't it? Look at where I am and what's happened to me! I have a right to be angry!" (pp. 248–249). Caden does not take his group therapy seriously and outsmarts the nurses by tucking his medicines into his cheeks. Although these are negative behaviors that impede his progress, they are also ways for Caden to have control over his thoughts and body at a time when he feels he has lost control.

In *The Unlikely Hero of Room 13B*, Adam uses medical knowledge to communicate with those who are and are not familiar with OCD. Although all of the teenagers in the group have the same diagnosis, Adam articulates the differences between teenagers with OCD: "Peter was going to be a problem. Or maybe he just needed a meds adjustment. With some in the

group it was hard to tell” (p. 4). Here Adam assumes the position of OCD expert, as he draws attention to the fact that one of his peers is in a worse state than he and needs desperately to be prescribed a different medication. Adam-as-pharmacist shows up at another point in the text when he talks to Thor: “I mean, meds and meds adjustments can mess you up almost as much as the OCD can” (p. 248). Adam’s knowledge of the ways in which OCD and medication complement one another reveals a deep understanding of the mental illness and the effects of his treatment options. In another scene, Adam embodies the language of a medical expert when he introduces his group mates to a priest: “Oh yeah, OCD is the major presenting and we’re all medicated and not violent” (p. 186). His language is similar to that which might appear on a patient’s medical chart. Adam gains agency by engaging in the medical discourse surrounding OCD.

We would be remiss if we did not acknowledge that this idea of patients as medical experts becomes complicated; in certain instances, the adolescents in these novels exemplify agency by acquiescing to the idea that medical help is needed and acknowledging the medical professionals’ expertise. We encourage discussions about whether adolescents acting as medical experts always means pushing back against medical professionals.

Relationships

Relationships are typically a central focus in YA literature, as they are in the lives of adolescents in general. One characteristic of “sick lit” in the tradition of novels such as Green’s (2012) *The Fault in Our Stars* is whirlwind teen romance against the backdrop of realized mortality. However, the three novels we read for this study do not consider terminal illness, but instead consider the stories of teens with chronic, and often invisible, illnesses that they must manage for the rest of their lives. Not surprisingly, these illnesses complicate the relationships the main characters have with parents, friends, and love interests. In fact, we noticed that the protagonists chose, albeit reluctantly, to prioritize management of their respective conditions over romantic relationships.

When Adam and Robyn first fall for each other in *The Unlikely Hero of Room 13B*, Adam believes that he can be “fixed” (p. 228), and he uses Robyn as his motivation to dream up a version of himself that is

not plagued by anxious thoughts. Because of Robyn, he theorizes, “His life was going to be perfect—better than perfect. Adam was on his way straight to *superior*” (p. 69), and he repeatedly expresses hopeful motivation, such as, “I have to get better for Robyn” (p. 228). However, Adam comes to accept that he must prioritize himself when he and Robyn break up, knowing they are not good for each other while she is in remission and Adam’s OCD is only getting worse.

Robyn directly acknowledges that in a difficult conversation with Adam, stating, “You’ve got to let go of all those distractions, all those extra worries, and concentrate on yourself” (p. 251). Though this breakup is difficult for Adam and Robyn, Adam knows it is necessary for his long-term health. Adam and Robyn’s love story does not become a clichéd

teenage romance. Instead, it represents Adam’s maturity and his desire to devote time to himself—an act of agency.

In *Challenger Deep*, Caden has a relationship with fellow patient Callie. This relationship is complicated and focuses significantly on the value of physical touch and human relationships in the sterile, controlled world of the hospital. Caden holds Callie’s hand despite the rules against it: “Sometimes I hold her hand—which, strictly speaking, we’re not supposed to do. No physical contact allowed” (p. 185). Caden notes that he does not care if the adults see him holding hands with Callie. In these scenes, we see how much Caden needs these humanizing moments. However, just as Adam and Robyn eventually realize the complicated nature of balancing love and mental health, Callie and Caden also realize that their relationship may be temporary. Callie says, “We have to promise to free each other when the time comes” (p. 215). Here, Callie reminds Caden that being “free” is a condition of their own making and not simply the whim of the medical professionals. While their doctor must “sign the papers,” it is, ultimately, the patient’s progress that determines release. Though Caden initially seems to miss Callie’s point in the above con-

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versation, he eventually realizes that setting her “free” means letting go of their relationship and focusing on getting better. These choices reflect the conflicts between two things Caden desires and the choice he must make to prioritize one over the other.

In *Because You’ll Never Meet Me*, Ollie and Moritz discuss in their letters the anxieties of capturing the attention of girls they know, but it is Ollie’s relationship with Liz that takes center stage. Liz is Ollie’s

neighbor and one of the few people with whom he can ever come in contact. Ollie struggles with the understanding that for someone to be in a relationship with him, she must give up going out in public together or participating in any activities that include electricity. Ollie is smitten by Liz: “It didn’t matter the sky was dark outside, that we needed our four lanterns to see by. She was lighting up the room for me” (p. 111). His attraction to Liz humanizes

him and helps him understand that he is more than a diagnosis. Liz tells Ollie that he should never mention his illness before mentioning his name. This language exemplifies how adolescents with mental or physical illness can gain agency through and because of their relationships. Liz and Ollie share a few kisses, even one that “didn’t suck” (p. 339), and whereas their relationship does not develop into something lasting beyond the book’s final pages, what Ollie learns about love and about himself through his relationship with Liz is powerful.

The realness of these teenagers’ relationships resists some authors’ well-intentioned decisions to allow teenagers with illnesses to engage in romantic relationships and friendships that are so unlike typical teenagers’ somewhat tumultuous and dramatic relationships and friendships. The rawness of the relationships presented in the focal YA illness narratives allows the teenagers to exhibit agency and shows them as just teenagers, not teenagers with an illness.

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Implications for Classroom Practice

YA illness narratives provide spaces for rich rhetorical analysis, interdisciplinary discussions, and writing assignments that have the potential to help students develop literary and nonfiction analysis skills. The lesson ideas we share below align with several components of the Common Core State Standards (National Governors Association Center for Best Practices & Council of Chief State School Officers, 2010), including identifying key ideas and details, focusing on craft and structure, comparing and contrasting across multiple texts, examining nonfiction texts, and composing narratives. Below, we suggest classroom activity ideas to engage secondary English students in discussions about how agency functions within YA illness narratives and encourage teachers to collaborate with colleagues from different content areas. Imagine how the literature and biology teacher and their students might approach these illness narratives in different ways. We acknowledge that some teachers may be hesitant to create new units of study for a variety of reasons; however, we encourage teachers to think about how the lesson ideas presented below may fit into existing curriculum units or guides on courage, family, friendship, hope, or injustice.

Fictional Illness Narratives versus Nonfiction Illness Narratives

Teachers might have their students compare and contrast a YA illness narrative with a nonfiction illness narrative. For example, one could pair:

- *Challenger Deep* with one of the stories from the World Fellowship for Schizophrenia and Allied Disorders (2009);
- *The Unlikely Hero of Room 13B* with a post from author Jackie Lea Sommers’s (*n.d.*) blog about her life as a published YA author and person with OCD;
- *Because You’ll Never Meet Me* with Abby’s story on the Pacemaker Club’s website (Pacemaker Club Inc., 2017).

These pairings could encourage discussions around how agency functions similarly or differently within fiction and nonfiction texts. Such discussions might help students think about how what is going on in YA illness narratives relates to real people and health initiatives, providing an opportunity for teachers to

integrate several content areas. Table 2 provides print and media nonfiction pairings for each of the focal texts.

Analysis of Representations of Illness in Scientific Texts

Yet another way to encourage interdisciplinary work is to have students examine the ways in which illness is represented in YA illness narratives and nonfiction science texts. For example, students can engage in a critical analysis of how OCD is represented in *The Unlikely Hero of Room 13B* and in an Anxiety and Depression Association of America’s (ADAA, *n.d.*) brochure (https://www.adaa.org/sites/default/files/OCD_brochure_rev.2014.pdf). After reading both texts, students could work in small groups to discuss the following questions:

1. In what ways are people with OCD positioned in these texts? What similarities and differences do you notice? Provide textual evidence to support your thoughts.
2. In what ways do the texts provide or not provide agency to people with OCD?
3. What changes would you make to the texts to ensure that patients had agency? Provide textual evidence to support your thoughts.
4. Recreate the OCD brochure in a way that positions adolescents with OCD as people with agency. Be able to support your decisions with evidence from the original texts and explain how the authorial decisions you made address the agency of adolescents with OCD.

Relatedly, students could examine how agency in *Challenger Deep* is presented similarly to or differently from the schizophrenia entry in the *Diagnostic and Statistical Manual of Mental Disorders* (APA, *n.d.*). Analyzing fiction and nonfiction texts about depression can engage students in discussions about how agency functions in each of these pieces and prompt them to think about how the patient is treated in YA illness narratives versus scientific literature about particular illnesses.

Analysis of Agency via a Text Set

Although the previous two classroom ideas focused on having students compare one text to another, we also think it is valuable to have students analyze agency through a critical literacy lens across the multiple texts in a text set. The themes we shared above (i.e., how patients articulate their illness, how patients reveal medical expertise, and how patients engage in romantic relationships) and others that emerge in the classroom can be the catalyst for discussions of agency across multiple written or visual texts. Stevens and Bean’s (2007) questions related to critical literacy can spark dialogue about agency: *Who/what is represented in this text? What is absent or not represented? For whom was this text written? How could this text be rewritten to convey a different idea/interpretation?*

Couser (1997) wrote about the lack of diversity in illness narratives, writing that nonfiction illness narratives are typically written by white, upper-class people who are already writers or professionals in fields in which writing is important. Students and teachers

Table 2. Fiction/nonfiction pairings for illness narratives

Fiction	Nonfiction	Multimedia
Shusterman’s (2015) <i>Challenger Deep</i>	Personal stories (World Fellowship for Schizophrenia and Allied Disorders, 2009)	NPR podcast: “Would you tell the world you have schizophrenia on YouTube?” (Chen, 2016) Video: “First Person Experience: Laura” (TeenMentalHealth.org, 2017)
Thomas’s (2015) <i>Because You’ll Never Meet Me</i>	Abby’s story on the Pacemaker Club’s website (Pacemaker Club Inc., 2017)	NPR podcast: “Headphones can disrupt implanted heart devices” (Shapiro, 2009)
Toten’s (2015) <i>The Unlikely Hero of Room 13B</i>	Website: “Jackie Lea Sommers” (Sommers, <i>n.d.</i>)	YouTube video: “The stereotypes and misconceptions of OCD” (White, 2014)

could do an analysis of a text set that includes the authors who compose (or do not compose) illness narratives, the characters who are (or are not) represented, and the illnesses that are (or are not) featured.

Allowing students to write about subjects that are uncomfortable and maybe even risky in the school setting . . . can provide student writers with the agency gained by the adolescents featured in the YA illness narratives.

Such an analysis could facilitate a discussion about why some races, genders, classes, and illnesses are privileged or underrepresented in YA illness narratives. Students might have a role in constructing the text set by reading YA illness narratives other than the focal texts (e.g., Thomas’s *Nowhere Near You* [2017], the sequel to *Because You’ll Never Meet Me*) during independent reading time or as part of a book club. The Goodreads “YA Illness” list and the Schneider Family Book

Awards can help teachers and students find additional YA illness narratives.

Composing Illness Narratives

Our final lesson idea involves asking students to respond to the YA illness narratives they have read and to the discussions prompted by some of the above lesson ideas in their own illness narratives (of those of people they know or about whom they have read in fiction or nonfiction). Recent scholarship (e.g., Bathina, 2014; Johnson, 2014) has discussed the challenges and power that can come from students sharing vulnerable moments in school writing assignments. As Johnson wrote, “Critical pedagogies like Freire, skeptical of teacher-centric formal schooling, cast students’ personal narrative writing as evidence of student empowerment” (pp. 575–76). Allowing students to write about subjects that are uncomfortable and maybe even risky in the school setting, as Johnson’s article discusses, can provide student writers with the agency gained by the adolescents featured in the YA illness narratives. Furthermore, asking students to hyperlink to particular scientific and medical terms within their illness narratives will emphasize interdisciplinary connections.

Students’ illness narratives can become a way to increase audience knowledge about particular illnesses, thereby embodying the “taking action” element of critical literacy often missing in curricula (Lewison et al., 2002). For example, teachers might encourage students to write their illness narratives with pharmaceutical or insurance companies in mind so as to facilitate critical thinking about the role corporations have in patient agency. Such work aligns with Freire’s (1970) idea of “problem-posing education” in which “people develop their power to perceive critically the way they exist in the world with which and in which they find themselves” (p. 64).

Conclusion

Contemporary YA illness narratives provide many opportunities for discussions of agency in the secondary English classroom. An analysis of these texts may provide ways for students and teachers to engage in interdisciplinary analysis characteristic of the medical humanities and called for within the Common Core State Standards (National Governors Association Center for Best Practices & Council of Chief State School Officers, 2010). Incorporating the medical humanities into the secondary English classroom through analyzing YA illness narratives may also help students understand the interconnectedness of content areas that are often presented separately. Students might consider the ways in which their English language arts course connects with their science and health courses—rarely discussed in connection with one another—and understand how these content areas inform one another.

Patients who write illness narratives gain agency, and doctors who read them gain an understanding of them as humans versus patients. In much the same way, the three focal YA illness narratives we have recommended here give adolescents a voice, be it spoken, electronic, or drawn, that counters ideas of adolescents’ lack of agency in medical spaces. Readers of YA illness narratives come to understand adolescents with illness as more than just patients. Not one of our focal books ends with just a diagnosis or a cure; their characters refuse to be defined by their physical or mental illness.

Exposing students to adolescents who have a voice, who are empowered, and who also hap-

pen to have a physical or mental illness can go far in a curriculum with social justice aims. Presenting adolescents with agency who are more than just ill bodies and minds, YA illness narratives can be used in the secondary English classroom to engage students in discussions and engaging activities that help them think critically about agency in these fictional depictions and in their lives. Whereas the depictions of illness in each of these three books are vivid and real and the diagnoses severe and grave, *people*, not patients, exhibit agency in these texts.

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Kathryn Caprino is an assistant professor of Education at Elizabethtown College. Her research is focused on new literacies, children's and adolescent literature, the teaching of writing, and technology integration in the literacy classroom. Prior to her doctoral work, she taught middle and high school English. Feel free to visit her blog, Katie Reviews Books (katiereviewsbooks.wordpress.com).

Tara Anderson Gold is a doctoral candidate at the University of North Carolina at Chapel Hill. Her research areas include young adult literature and new literacies, and her dissertation study examines literacy practices on YouTube. Prior to her doctoral work, she was a librarian and middle school English teacher. You can read her blog, The Librarian Who Doesn't Say Shhh!, at <https://librarianwhodoesntsayshhh.com/>.

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