

Teaching YA cancer narratives: The Fault in Our Stars and issues with voicing illness

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Abstract

Increasingly publishers are promoting illness as a commodifiable literary product. There is now a wide range of autobiographical and fictional texts that explore life-threatening illnesses from the embodied perspective of protagonists. This trend is also evidenced in the content of young adult literature where concepts of the diseased self, agency and mortality are explored. The aim of this paper is to provide some background context on illness narratives and offer a close reading of the young adult text, *The Fault in our Stars* by John Green, in order to highlight important issues such as the accurate and realistic portrayal of cancer, particularly in the lived experience of adolescent readers. It is anticipated that this discussion will allow classroom teachers to engage more fully in conversations about text selection and content, and the ways in which literature can advance realistic representation of illness that previously

have been culturally taboo.

Introduction: Teaching Cancer Narratives

“When you learn your life is threatened, you can turn toward this knowledge or away from it. I turned toward it”
(*Intoxicated By My Illness*, Anatole Broyard)

The following paper provides key insights into the burgeoning field of autopathography and illness narratives. Increasingly publishers are promoting illness as a commodifiable literary product. There is now a wide range of autobiographical and fictional texts that explore life threatening illnesses from the embodied perspective of protagonists. This trend is also evidenced in the content of young adult literature where concepts of the diseased self, agency and mortality are explored. Such thematic focal points invite English teachers to further examine this narrative shift and to critically engage with the ethical stance of a text, and the ways in which illness is legitimately and accurately portrayed.

The central aim of this paper is to provide some background context on illness narratives and authorial motivation in using writing as a means to reduce marginalisation and stigma. Importantly, we offer a close reading of the young adult text, *The Fault in our Stars* by John Green (2012), as a

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strategic means to reflect on important issues such as the accurate and realistic portrayal of cancer, particularly in the lived experience of adolescent readers. By exploring these ethical issues we anticipate classroom teachers can engage more fully in conversations about text selection and content, and the ways in which literature can advance realistic representation of illness that previously have been culturally taboo.

Illness narratives

In the opening pages of his autobiographical text *Intoxicated By My Illness*, Anatole Broyard (1993) highlights the impulse to write about illness rather than suppress his response to a cancer diagnosis: “when you learn your life is threatened, you can turn toward this knowledge or away from it. I turned toward it” (p. 3). His confession is indicative of an observable narrative shift in contemporary writing, as Schultz and Holmes (2009) point out, where “cancer exceeded its discursive boundaries as a biological entity and became the focus of intense cultural interest” (p. xi). They posit that the “shifting relations between patients and medical practitioners ‘helped promote ...’ the flowering of cancer narratives” (p. xi). Increasing emphasis on the autonomy of patients and a “resistance to the authority of the medical gaze or the inhumanity of medicalized settings” (Shultz & Holmes, 2009, p. xi) has also motivated marginalised subjects to take up speaking positions.

These increasing accounts of authors telling personal experiences are often called autopathographies. Anne Hunsaker Hawkins (1999), in her foundational work highlighted one of the primary functions of writing this kind of genre: “patients not only restore the experiential dimension to illness and treatment, but also place the ill person at the very centre of that experience” (p. 128). She also observed that this mode of narration not only situates illness, and its treatments, within the author’s life, but also links them with “the meaning of life” (p. 128). As a cancer diagnosis can be destabilising and the invasive treatment dehumanising, autobiographical writing offers an opportunity to counter this sense of fragmentation through authoring/producing a coherent and manageable text.

In looking at the ways in which such stories about illness are variously structured, sociologist Arthur Frank (1995), in his influential text *The Wounded Storyteller*, offers three classifications of illness narratives. Firstly, the “restitution narrative” (pp. 75-96) has at its structural base the movement from illness back to restorable health. There is a sense in which the “happy ending” drives and shapes the text. Then there is the “quest narrative” (pp. 115-136),

which does not necessarily promise a neatly resolved health outcome, but focuses on the way in which difficulties are approached and suffering confronted with a view to important life lessons being learned along the journey. The third form of illness story, the “chaos narrative” (pp. 97-114), as Frank indicates, is the most difficult to tell, and the most difficult to listen to (or read). This is because it is “the anti-narrative of time without sequence, telling without mediation and speaking about oneself without being fully able to reflect on oneself” (p. 98). This kind of narrative is founded on the anxieties, and melancholia, that so often can be produced when the prospect of recovery is rendered impossible by chronic or terminal disease.

While we acknowledge we have by necessity over-simplified Frank’s narrative classifications here, even a rudimentary understanding is helpful when talking about the structural techniques frequently employed by a story teller who wishes to communicate an illness experience. However, sometimes a single text may simultaneously be shaped by all of the multivalent trajectories of “restitution”, “quest” and “chaos”.

Because, as Frank (1995) testifies, an illness diagnosis can be disruptive and the intrusive treatment dehumanising, autobiographical writing offers an opportunity to counter this sense of fragmentation through authoring/producing a coherent and manageable text. And, as Roscoe (2016) highlights, these kinds of illness texts are increasingly popular with readers because “... we are drawn to human stories of adventure, suffering, loss and other examples of extreme experience and emotion, and to stories that allow us to vicariously experience various aspects of the human condition” (p. 68). While such stories engage audiences, Ann Jerecic (2012) highlights “Such an approach to personal narrative is, however, out of step with mainstream literary criticism, which has not, by and large, recognized the significance of the work performed by such texts” (p. 3). While the academy may be reluctant to privilege the work of personally mediated stories on illness, popular audiences place value on such texts.

Part of the appeal these human stories have for readers can be inextricably linked to the status of a text’s perceived authenticity. When an illness narrative is a first-hand account of a patient’s lived experience of illness and its treatment, the text is often privileged as an agentic and therapeutic work, and its veracity remains uncontested. As Couser (1997) notes, works of this kind typically perform the work of “recover[ing] variously dysfunctional bodies from domination by others’ authority and discourse ... [and thus] convert the passive object into active

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subject” (p. 291). In underscoring why he believes such texts have value, Frank contends that “Through their stories, the ill create empathic bonds between themselves and their listeners” (Frank, 1995, p. xii).

Messaging the real

Health communication has often utilised reason based approaches within messages on the assumption that a more informed and knowledgeable individual will take note of the message. This approach, based on the Health Belief Model (Rosenstock, 1974, p. 330) has been challenged more recently by the expansion of testimonial stories on illness experiences. It is apparent that for many the experience of illness and the consequent interaction with the health care system brings an undeniable urge to search outside the medical boundaries for more (Broom, 2005; Kivits, 2004; Nielsen, 2010). Dolce (2011) identified two strong themes driving such individuals. Firstly, there was considerable disenchantment with the interactions with health care providers and secondly frustration with the health system. In embarking on this search individuals will quickly become exposed to numerous narrative style sources of information written outside a biomedical framework. In the case of cancer, narratives have become a common outlet for individuals. Given the rising popularity of this style of communication, it has been compared to an instructional style and it is clear that the narrative approach connects better with an audience (Kreuter, Holmes, Alcaez, Kalesan, Rath, Richert, ... Clark, 2010).

One might question to what extent fictional works or illness narratives impact the health of the wider community and whether accuracy in fictional work is therefore a concern. This is not a recent issue given that in 1904 the Journal of the American Medical Association published an article titled “Medical errors in fiction” decrying the inaccuracies in fiction when describing medical scenarios (Journal of the American Medical Association, 1904).

The experience from the field of mental illness gives solid evidence of the persuasive and negative influence that inaccurate and distorted messages lead to. For instance, Wahl (1995) identified examples of the numerous ways mental illness was depicted in negative ways in various media, including that orientated to children and youth. This has been a concern that many medical professionals have held because of such stigmatising leading to negative views, fear and prejudice. Byrne (1998), a senior registrar in psychiatry, lamented the ways misinformation in the media perpetuated what he labelled “the spurious association between all mental illness and violence” (p. 176). This groundswell of

concern in the community and medical profession, led to the Royal College Christmas Lecture for Young People being orientated to this topic with the debate titled, “Mental Illness and the Media”. Bolton (2000) in this address expressed this well in relation to other unacceptable forms of stereotyping observing, “Racism and sexism are unacceptable, but we lack an equivalent term for the prejudice which surrounds mental illness” (p. 345).

Wahl (2003) later took the analysis further and particularly examined children’s media for ways that this depicts mental illness to children. He identified numerous examples of messages embedded in television, movies and books, of negative stereotypes and misinformation that perpetuate incorrect messages that are ultimately detrimental to health. Examples given come from the *Harry Potter* series where an escaped prisoner is identified to the young wizard as mad and a danger to anyone who crosses him, and the *Green Lantern*, where a character called Nero starts out in a psychiatric facility with an illness then this is linked to his villainous behaviour (Wahl, 2003).

These occurrences are not isolated to a brief period of time, but extend across decades and have perpetuated considerable inaccurate information. Klin and Lemish (2008) identify a number of examples where negative influences arise and this again included the genre of fiction. This negative framing as identified by Sieff (2003) influences public opinion and attitude not just in adverse ways, but often in durable imprints that are difficult to amend. Sieff indicates that this is particularly related to the way cognitive models of framing are postulated to work. Stories are the basis for understanding events, and for storing information, which when stored in this form become easier to retrieve as the items are linked, and subsequent recognition of elements of this framing triggers associations. In regards to the impact of a story, Caputo and Rouner (2011) in studying the effects of stories related to mental illness, found that the genre of a story, whether fiction or non-fiction, did not affect the impact in situations of familiarity with illness. What was key, was the relevance of the story to the individual and then regardless of the genre, the reader was more likely to be transported into the story, then experiencing less social distancing and greater involvement in the story.

There are a number of calls for medical fiction to be careful with the depiction of illness. Collee (1999) argues that there is a delicate trade-off between an accurate but bland story. Scenes involving suicide are especially seen as problematic, but he argues against a type of censorship for such activities, identifying a difficulty in determining where to draw

“*Racism and sexism are unacceptable, but we lack an equivalent term for the prejudice which surrounds mental illness*”

a boundary given similar concerns with violence, or unsafe sex amongst others. Charpy (2014) identifies a particular concern with fiction that is written by authors that have a background in medical care because of a perception of the work having greater authenticity, given the professional knowledge and experience of the author. Robin Cook is a particularly prominent figure in this category given his training in medicine. This perceived authenticity lends greater credibility to the text and this, combined with the seemingly detailed accounts of medical procedures and treatments, draws the reader in. Belling (2010) focuses especially on a Robin Cook novel, *Coma*. This text, with its detailed and graphic portrayal of the supposed advances in technology bringing about the dilemma of treating a person with a functioning body, but with a limited functioning brain, gave the public an insight into the notion of re-defining death. It was seen to spur an unaware public into a bio-ethical debate about death and end of life, but came with a dark side of a “sinister subtext of conspiracy, profiteering, and murder” (Belling, 2010, p. 450), thus creating a heightened anxiety regarding personal safety in hospital environments.

“Does this text voice illness, fictional or not, in a way that creates agency and empowerment for the reader?”

Fictional pathography and *The Fault in Our Stars*

While fictional pathography might create an empathic and authentic bond between an ill narrator and the reader, we acknowledge that imaginatively rendered texts might raise and compound further ethical questions about authorial motivation, and the reliability of truth telling. By way of exploring such writerly and readerly tensions we will look at Green’s (2012) *The Fault in Our Stars* and consider some of the key questions the text, and its representation of a teen cancer experience, raises.

Green makes it clear in his author’s note that *The Fault in Our Stars* is “a work of fiction”, that he “made up” and that he believes that any attempt to see it as factual attacks “the very idea that made up stories can matter” (Green, 2012, author’s note). While it appears that he is referring to the fictional nature of his characters, the nature of the statement would suggest that he believes a fictional account of illness to be accountable only in so far as it is true to its characters. If this is true, then it would appear he has not attempted to create an accurate cancer narrative, but rather a coming-of-age young adult novel that uses cancer to create drama and the high-stakes of near death experience. The main characters, Hazel and Augustus, are recovering from cancer – thyroid in Hazel’s case, with a satellite colony in her lungs (p. 5). Augustus has lost his leg to osteosarcoma (p. 11). The story follows their love, resistance to love, and their desire to find both a place and an identity outside of illness. Hazel is terrified she will

die and hurt Augustus, ironically failing to see that it is Augustus whose cancer has recurred. The two meet at a cancer survivor’s support group that Hazel openly despises. They find in each other their intellectual and emotional equals – both approaching their cancer experience with mordacity and a vaguely implausible philosophic eloquence. Fiction it may be, but it also positions itself as a pathography and thus it presents to an audience, in this case an audience generally too young to be intimately acquainted with cancer, a narrative of illness that will be their first and, in some cases, only experience with a cancer journey.

The text raises a constellation of questions: Does it matter if a piece of fiction represents illness in a fictional way? Can’t a story be just that – a story? Why shouldn’t a work of fiction manipulate an experience to heighten drama and to work more fluidly within the parameters of the narrative? We would posit that taking into consideration literary integrity and medical and psychological perspectives, it does matter. While there is room to creatively manoeuvre any lived experience within fictional frames, readers increasingly have come to expect more from fiction in terms of depictions of race, of gender and of disability – why would we expect less ethical alignment with reality from an illness narrative?

As interrogators of the *The Fault in Our Stars* we are interested in several questions. Does this text voice illness, fictional or not, in a way that creates agency and empowerment for the reader or does it advance the cliché that proximity to death creates profundity? Is it helpful for teenagers to see characters who are so eloquent in their storying of illness or does it create a false sense of the attractive and articulate nature of the cancer patient? Most importantly we ask of the text, does the voice actually advance an understanding of illness or simply present an emotional melodrama where young adult cancer patients are defined by their cancer and the experience of the disease becomes their entire world?

The cancer narrative in *The Fault in Our Stars* (Green, 2012) is presented intellectually – as perceived and understood by its well-read, mature and verbally dexterous protagonists. They are witty and caustic in the way they discuss their illness – at once claiming to be more than their cancers, and yet joking about survivor’s “cancertastic pasts” (p. 5) and the “cancer perks” that regular kids don’t get (p. 23). Hazel is flippant about her side-effects – the chipmunk cheeks and the fact that she was “veritably swimming in a paralyzing and totally clinical depression” (p. 4). The pair speak in metaphors and use ancient Greek terms for complex

emotional issues – “But of course there is always a harmatia and yours is that oh, my god, even though you had freaking cancer you give more money to a company in exchange for the chance to acquire yet more cancer” (p. 20). “It’s a metaphor,” he said. “You choose your behaviours based on their metaphorical resonances... I said” (p. 21).

Hazel and Augustus get to know each other to the backdrop of a mutual friend losing his eyesight to cancer and Hazel’s own hospitalisation due to the complications of her illness. Hazel’s desire to spare Augustus pain causes her to attempt to end the relationship before it can become serious, but Augustus persists and the two of them embark upon a quest to meet Hazel’s favourite author – the writer of a ‘cancer book’ himself – *An Imperial Affliction*. The two fall in love, make love and in the end, despite their desire to be more than, and outside of their own cancer – it is the cancer that not only brings them together, but ties them together beyond death. In Augustus’ words – they leave “scars” on each other (p. 311).

Green (2012) has called the book a “story about dying teenagers”, one that he tried to keep both funny and romantic in the hope that would not become “too wrenching” (Talbot, 2014, para. 15). The story is heavy, difficult and often dark, and it feels like there is little hope in any of the cancer narratives presented within the text – even the survivors have broken spirits and cannot engage meaningfully with the world. *The New Yorker* describes it as flying in the face of “the notion that romance, particularly about teenagers, has to be straightforwardly aspirational” (Talbot, 2014, para. 13). What it also flies in the face of, however, is the fact that a cancer narrative needs to be grounded in a realistic experience.

Reader reception

Teen cancer survivor S.L. Huang (2015) describes her response to *The Fault in Our Stars* as being one of frustration: “The fact that it claims **not** to be a ‘cancer book’ is all the more frustrating when it’s pretty much the canceringest cancer book ever to cancer-book” (para. 2). She claims the poor understanding of cancer patients and repeated inaccuracies are both monotonous and strangely boring. “There’s certainly an argument to be made that some people somewhere will react to paediatric cancer the way Green’s characters do. But that argument feels flimsy to me” (para. 6). Huang particularly dislikes the fact that Green’s characters first claim to be more than their cancers, and then prove the opposite through their choices and words:

Most saliently, all of Green’s characters have lives that revolve entirely around their cancers.

This is the most troubling aspect of the book for me. Despite their proclamations to the contrary... the characters are shown to have nothing in their lives that isn’t about their cancer. Even Hazel’s reading choices and Gus’s videogame-playing are reflections of their reactions to cancer. (para. 9)

In further critiquing the way in which *The Fault in Our Stars* depicts cancer patients as particularly profound and wise, Huang (2015) describes being “exhausted by both Hazel and Gus’s existential ridiculousness” (para. 17). Cancer, she explains, never made her profound – just angry. None of the other cancer patients she encountered spoke with the level of eloquence or understanding that Green’s characters display – they were, in Huang’s own words, “just kids” (para. 19). Others have echoed her view, one teen reviewer suggesting that the problem with

indicating that your characters are intelligent by giving them all the voice of a 30-year-old Yale English Lit major who is trying to impress a date, is that it is not great writing. It is mediocre writing that tramples and ignores and substitutes any genuine character voices with your own... Hazel is John Green. Augustus is John Green. Hazel’s mom and dad are John Green. Isaac is John Green. (X, 2012)

Author Tim Challies (2014) further critiques the novel as having “characters who have the philosophical background, verbal expression, and vocabulary of people much older than them” (para. 7). English author Mal Peet (2013) suggested that much as he “would love to meet teenagers such as Hazel and Gus” he fears he never shall “for surely such erudite, witty, philosophical, generous, courageous and doomed young people never walked the earth, let alone Indianapolis” (para. 6).

This sense that the characters are “more than” and even “better than” the average teenager, makes their response to their illness and mortality an unattainable one. The characters show maturity and understanding beyond the believable for young people who have had fractured education and low levels of socialisation, and this in turn portrays an experience that is not grounded in the realities of either cancer, or the experience of the teenager with cancer. This dichotomy between lived experience and the written one means that myths about death and profundity and “specialness” are perpetuated. Author Mal Peet (2013), describes the text as “faster off the mark and quicker on its feet than deep thought. The problem with smartness is that it tends towards aphorism” (para. 8).

That adolescents suffering with cancer will be grappling with the bigger existential question of

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life, death and meaning while going through an endless round of tests, scans and treatment, is a largely unfounded assumption. Such an assumption ignores developmental theory which suggests that life tasks differ throughout life and that these are chronologically ordered (Erickson, 1950). The depiction of adolescents who process trauma like a self-reflexive adult becomes somewhat implausible in this text, and the expression of strong emotion (which adolescents often exhibit) should not be confused with the more sophisticated existential inquiry portrayed in *The Fault in Our Stars*. This is not to say the text was not loved by its readers, the majority of whom were participating in the cancer experience vicariously.

In an episode entitled 'Books that Transport You' which aired on ABC's *The Book Club* panellists were asked to recommend a work that fulfilled this brief. Well-known comedian Kitty Flanagan offered *The Fault in Our Stars* as her choice, noting "... this felt like a worthy text". Comparing the female protagonist in Green's text to her own teenage self, Flanagan moves towards self-flagellation:

.. oh, god, I should have been nicer, I should have been better. Maybe it's because if you have a terminal illness you have to get your house in order and you have to be a little more grown up about things so therefore she was obviously a more astute and aware teenager than I ever was...

(Flanagan, 2016)

This notion of a "worthy" text can in part explain why the book was on the best-seller list for over 120 weeks and was made into a successful motion picture (Talbot, 2014). And amongst the community of teen cancer survivors Green has had his supporters. In one online fan meet-up, reported by the *New Yorker*, a fifteen-year-old girl, also an osteosarcoma sufferer, told Green that he had done "an amazing job of capturing the fear, the humour, and the real pain of being a teenager with cancer" (Talbot, 2014, para. 68). But, this does not appear to be the experience of many of the readers with a lived cancer experience. Journalist Tanith Carey (2013) is far harsher in her critique, describing the text as "mawkish at best, exploitative at worst" (para. 1). She sees this as more than a problem of their representation as remarkable teenagers. To Carey, the greater problem lies in the teen cancer experience being bled to provide dramatic tension and its development into a "sick-lit" genre with blurbs that "trip over themselves to promise their books will drive readers to tears or leave them devastated" (para. 12).

The representation of teens not as they are, but as they would "like to be seen" could be seen as problematic if seeking to voice a realistic and

empowering cancer narrative. For example, the erudite philosophies and high-level vocabulary of the main characters in *The Fault in Our Stars* limit the audience of the book to a subset of younger readers who have had the advantage of access to education, literacy and books. Wolf, Coats, Enciso and Jenkins (2011) describe the YA readership as a "privileged subset of a much larger group" (p. 23) and Garcia (2013) agrees – there is, within this genre generally created for marketing rather than readership – a strong bias towards the white, literate and socio-economically upper middle class (p. 19). This group of readers is not representative of those who have faced youth cancer, as cancer amongst teenagers is not linked to socio-economic factors and crosses borders of race and literacy (Clegg, et al., 2009). Cancer is not choosing white, upper-socioeconomic kids with strong family support structures, higher IQs and access to both quality education and cutting-edge cancer treatments.

The Fault in Our Stars is speaking to a cancer narrative different than that lived by most patients, a dramatic, romantic and deeply philosophical one. The result is an entertaining and moving story, but not an empowering narrative about the nature of the teen cancer experience. As survivor Huang (2015) laments, "I do not exist to be *your* tragedy. I do not exist for you to find special meaning in your life. I do not exist to teach people lessons or to give people feels" (para. 41).

The notion that teens can not only articulate their response to cancer with the precision of Hazel or Gus, but also respond to death with a profundity and existential awareness at the level Green demonstrates, is somewhat problematic. It suggests that, while the characters have been disempowered by their physical bodies, they have compensated for this with an evolved, and quite unlikely, level of intellectual acuity. The cancer patients of *The Fault in Our Stars* are depicted as either simpering survivors who cannot find an identity outside of cancer (as epitomised by the leader of the group therapy sessions) or they are the judgmental, snarky and formidably cerebral battlers. The text seems to suggest that the closer one comes to death, the more articulate and sagacious one becomes – particularly embodied by Gus. For the vicarious cancer-free reader, this may not at first seem paradoxical – what does it matter if the cancer experience is expressed realistically, if it is expressed in a dramatic way? But for the cancer sufferer or survivor, this advancement of cliché leads to a narrative that is at best misrepresentative and at worst misleading.

Other young adult fictional pathographies

Several other fictional pathographies have emerged

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in the young adult space in recent years, though none as popular in terms of sales as *The Fault in Our Stars*. These texts vary in their approach to illness, some tackling the grit of everyday physical illness head on and other taking a more metaphorical approach. Jenny Downham's (2008) *Before I die*, is an intricate exploration of the physicality of cancer. Downham says of the character in her book with terminal cancer,

I wanted the reader to inhabit her body ... in the hope that they would have both a visceral and an emotional response. If Tessa's body does the talking—if the reader experiences a lumbar puncture or a haemorrhage with her—then it inevitably pushes the reader closer to the physical self. I wanted to achieve an immediacy between the body's decline and the words Tess uses to describe what's happening to her.
(New York Times, 2007, para. 10)

While Downham (2008) claims to have consulted oncology staff to keep the story medically factual, she is quick to point out that her plan was never to write a 'medical story', something that mirrors Green's own claim (*New York Times*, 2007). However, her story involves such an intimate portrait of cancer that it will likely be read as a potentially real, lived experience by her readers. Her character, Tess, is not as eloquent as Hazel or Gus, but is just as poetic, expressing herself in rich imagery:

when I die, I'll return to dust, glitter, rain.... I want to be buried right here under this tree. Its roots will reach into the soft mess of my body and suck me dry. I'll be reformed as apple blossom. I'll drift down in the spring like confetti and cling to my family's shoes.... In the summer they'll eat me
(Downham 2008, p. 283)

However, there is something of Tess that is simpler and less contrived than the characters of *The Fault in Our Stars*; she is not waxing philosophic, but rather expressing clearly a desire to live, something that can be understood on a level that transcends a cancer diagnosis. Tess is not an unrecognisable character – too smart and too witty. She is every teenager facing the things that scare them most – “I want you to be with me in the dark. To hold me. To keep loving me. To help me when I get scared. To come right to the edge and see what's there” (Downham 2008, p. 256).

Patrick Ness' (2013) *A Monster Calls* does not explore cancer realistically as Downham or Green do, using instead the fantastical metaphor of a monster to unlock the grieving and fear response in a stoic child dealing with his mother's cancer. The reader is distanced from the character with cancer,

exploring instead the emotional response of the loved one. Illness is the ominous presence in the story, but not the focus. Alice Kuipers' (2008) *Life on the Refrigerator Door* creates a similar distance between the character of Claire and her mother Elizabeth after her mother's cancer diagnosis and eventual death. They communicate via post-it notes on a refrigerator which makes the book an emotional journey about illness, goodbyes and grief rather than one about cancer itself; in fact, even Elizabeth who is an obstetrician-gynaecologist appears to have very little knowledge of breast cancer.

Issues with fictional and inaccurate pathography: Bibliotherapeutic use of literature

Of course, books about teen cancer are not only read by the teen cancer patient, in fact the larger part of the audience will be those with no experience with cancer at all and therein lies the dilemma for the educator. Is an inaccurate pathography, even a fictional one, providing students with a false narrative and understanding of illness, something that will affect how they themselves respond to illness in their own lives or in the lives of others? What is the responsibility of the educator to look for accuracy in a fictional pathography?

In an essay titled “Reading for Life” Martha Nussbaum (1990) notes that “People care for the books they read; and they are changed by what they care for - both during the time of reading and in countless later ways more difficult to discern” (p. 231). Nussbaum's comments on reading also suggest something of a bibliotherapeutic process where, as Briggs and Pehrsson (2008) highlight, books function as “a mechanism that assists with making meaning from life experiences, draw[ing] upon characters or information to expand worldviews and to assimilate new knowledge” (p. 37). This bibliotherapeutic relationship to texts indicates something of the multimodal nature of literature that is able to excite “the imagination so that readers recognise *actual* worlds and, simultaneously, create *possible* worlds” (Hodges, 2010, p. 65). A reader might seek to employ *The Fault in Our Stars* in this expansive way to understand a cancer diagnosis and treatment, reflecting not only on “what *is* or what *was*, but also asking what *might* be” (Hodges, 2010, p. 65). However, while *A Fault in Our Stars* might function in a therapeutic way for some readers, it could easily problematise realistic understandings of the actual and possible worlds for other readers.

This is where a new issue could manifest itself as a potentially troubling one - the relationship between helper and sufferer. Those who have read stories of cancer, but not lived it, are more likely to base their interactions and beliefs about cancer on

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An unrealistic portrayal ... an inauthentic picture ... may result in an incongruence between what the helper believes versus the ... actual lived experience.”

“it is important that those who are to provide emotional support come, ... from a place of ‘not-knowing’ ... being willing to listen and journey with the ... cancer patient.”

the stories they have heard. Carl Rogers (1992), one of the founders of humanistic psychology, identified unconditional positive regard, empathy and congruence as the key conditions that must exist for a therapeutic encounter to be successful. An unrealistic portrayal of the experience of the adolescent cancer sufferer, provides an inauthentic picture. This may result in an incongruence between what the helper (be they nurse, social worker, psychologist, counsellor or any other professional that may be involved in assisting the teen with a cancer diagnosis) believes is occurring versus the actual lived experience. Introducing elements not likely to be present in a lived journey gives an unhelpful bias to the person interacting with the person experiencing cancer. This may have implications for communication and behavioural interventions. In the case of family, friends and other non-professionals involved with the adolescent, their skewed perception makes it more difficult to provide empathy. Empathy by its very definition necessitates congruence (Rogers, 1975) and can be hindered by a glamorised or sensationalised portrayal of what it means to receive a terminal diagnosis. As the cancer experience already involves a lot of interaction with professionals who are administering treatment from a position of authority, it is important that those who are to provide emotional support come, as far as is possible, from a place of ‘not-knowing’ and thus being willing to listen and journey *with* the adolescent cancer patient. Such a relationship requires humility and congruence, resulting in the formation of an empathic connection. The creation or promulgation of stereotypes does not aid in this already complex endeavour. Thus, if this text is used in an educational setting, it seems essential that this consequence of the glamorisation of the cancer journey be enunciated clearly. Teens need to be able to journey with other teens in a congruent and empathic fashion.

Conclusion

While these are very different approaches to representing cancer as a subject, or even as a background catalyst, what does appear to be consistent across teen cancer narratives is death. Cancer equals death for most of the characters it touches, something that creates a sense of doom around the disease that simply does not reflect the medical facts and feels contrived to create melodrama and emotion. This is not to say the texts are without merit, it is just to suggest that this merit does not extend to the illumination of the real, lived experience of illness that Frank (1995, 2013) discusses in *The Wounded Storyteller*. Those pathographies, which allow the cancer patient a

voice and a bond between themselves and those who read their stories, enable the ill both a sense of connection, and ownership over their bodies and illnesses, and these are reliant upon the veracity of the text. The fictional pathography has no such need for truth or to provide a voice for the ill and can be exaggerated, changed and made eloquent for the sake of appeal to an audience. This, in turn, creates a sense that those with an illness will behave, speak or connect in a way that may not be authentic. The truth-tellers may not be as verbally dexterous as the fictionally ill and their narratives slower and less dramatic. In the case of *The Fault in Our Stars*, Green has created characters with dramatic illnesses, false cures and an understanding of self and existence that is at odds with their life experience and education. As teen cancer survivor Huang puts it – the books uses cancer as some sort of lens for the meaningfulness of life (Huang, 2015). Rather than telling a cancer story in a way that illuminates the illness experience, *The Fault in Our Stars* uses cancer as a way to create tension, fear, drama and eventually tragedy. It is cancer as plot device, rather than cancer as the catalyst for works that might allow for a greater understanding of illness and the ill. This usurping of the patient voice is an important issue for the educator to consider before using a fictional pathography as a text set for teenagers – is the text enhancing their understanding of illness and providing an accurate empathetic response? Or is the text providing an unrealistic and false narrative that does a disservice to the lived experience of their peers? The true, lived pathography will provide the teenage reader and student with a greater knowledge of their world and the experience of those around them. **TEACH**

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