

How *The Fault In Our Stars* Illuminates Four Themes of the Adolescent End of Life Narrative

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ABSTRACT

Adolescents who face life limiting illness have unique developmental features and strong personal preferences around end of life (EOL) care. Understanding and documenting those preferences can be enhanced by practicing narrative medicine. This paper aims to identify a new form of narrative, the Adolescent End of Life Narrative, and recognize four central themes. The Adolescent EOL Narrative can be observed in young adult fiction, *The Fault In Our Stars*, which elucidates the notion that terminally ill adolescents have authentic preferences about their life and death. Attaining narrative competence and appreciating the distinct perspective of the dying adolescent allows medical providers and parents to support the adolescent in achieving a good death. By thinking with the Adolescent EOL Narrative, adults can use Voicing my CHOICES™, an EOL planning guide designed for adolescents, to effectively capture the adolescent's preferences, and the adolescent can make use of this type of narrative to make sense of their experiences.

I. Introduction

Narrative ethics uses stories to create space for dialogue, interpretation, and exploration. In medical ethics, narrative can be a tool of moral reasoning, and rather than thinking about stories, we can cogitate with them.[1,2] Caring for others through narrative confers empathy and recognition of human plight.[3] The humanities, particularly literary works, provide a platform for studying and developing a deeper understanding of the human experience of illness.[4,5] "Narrative medicine," the application of narrative competence, which allows the provider to practice insightfully and empathically, should be employed when engaging terminally ill adolescent patients. [4]

A review of the literature suggests a dearth of information on how young adult (YA) literary works can be used to better understand adolescent end of life (EOL) decision-making. This paper proposes that fiction can offer insight into adolescent thinking, particularly when an adolescent's temporal experience is unnaturally scrambled. Furthermore, we propose that the Adolescent End of Life Narrative is a distinct type of narrative that can be useful for clinicians and parents when shepherding an adolescent through a change in their life trajectory as the result of a life limiting illness. This form of narrative can also be used by adolescents themselves as they make sense of their altered life course.

As discussed in more detail below, there are a number of literary works in both fiction and non-fiction that can serve as useful models in this endeavor. However, we rely on the popular YA novel *The Fault in Our Stars* (TFIOS) to illustrate both the form of the Adolescent EOL Narrative and the utility of those texts that take this form.[6] TFIOS spent 124 consecutive weeks on *The New York*

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Times best seller list and enjoys broad appeal among teens and adults, both as a book and a film, which is loyal to the novel.[7] Although many different stories can demonstrate the Adolescent EOL Narrative, *TFIOS* is well-regarded for capturing the adolescent voice; indeed, author John Green has been called “The Teen Whisperer.”[7] This literary work gives voice to the unique and complicated factors facing an adolescent with life limiting illness and lays bare the struggle between an adolescent’s fierce desire to become independent and unmistakable reliance on family to meet their medical, and even social, needs.

Finally, this paper posits that tools such as Voicing My CHOICES, designed for adolescents to identify their EOL preferences, serve as a template for self-expression and are in many ways themselves the creation of a new narrative, one organized around goals, hopes, regrets, desires, relationships, and visions of legacy.[8] Medical providers and parents can and should incorporate elements of Adolescent EOL Narrative when helping patients express their wishes in Voicing My CHOICES, or similar documents. Thus, reflecting on Adolescent EOL Narratives such as *TFIOS* can assist adolescents, medical providers, and surrogates in articulating EOL preferences that authentically reflect a patient’s values and wishes.

II. Decisional Capability of Adolescents

Adolescents facing life limiting illness, like the protagonist in *TFIOS*, experience daily struggles, years of invasive treatments, and acute hospitalizations. Despite their age, adolescents mature quickly as they become intimately familiar with and knowledgeable about their disease process.[9] They have personal knowledge of their own suffering, including what treatments cause pain or weakness, and what medications offer relief.[9] They may have witnessed the death of similarly situated friends.[9] “They have had, at the very least, multiple opportunities to think about the inescapable suffering that characterizes their lives, the features of life that make it worth continuing, and benefits and burdens that accompany medical treatment, and the prospect of death.”[9]

Adolescence can be broken down into three stages: during early adolescence (age 10-14) children shift their attachment from parents to peers; middle adolescence (15-17), teens focus on “self-image, feelings of achievement and power, experimentation, and advancement of logical thought with a capacity for abstract reasoning”; and late adolescence (~20 years old), when young adults have an awareness of and appreciation for relationships with others and a greater sense of self-assurance.[10]

Although children and adolescents under the age of 18 generally lack the legal authority to make medical decisions, there is consensus that cognitively normal adolescents, sometimes as young as 12 years old, have the capacity to make medical decisions.[11] Age, family affluence, and health literacy are predictors of adolescents’ enhanced understanding, appreciation, and reasoning.[12] Children as young as eight can begin to grasp the permanence of death; however, a mature appreciation of death depends largely upon the child’s exposure to the death of another.[10,13] Ten year olds with advanced cancer may be able to comprehend EOL decisions.[14] This theory relates to Sarah Lochlann Jain’s concept of “living in prognosis”; adolescents with life limiting illness start to decipher mortality at a younger age, as that child’s prognosis brings him closer to death.[15] The

adolescent's temporal experience shifts away from a focus on social and physical growth, toward a world of procedures, treatments, hospitalizations, and uncertainty. For chronically ill teens "adolescence is a paradox of emerging capabilities and diminishing possibilities."[10]

Parents and providers are more likely to accept and support an adolescent's decision to withhold or withdraw care if they feel confident that the adolescent makes authentic and logical choices, understands their illness, and demonstrates the ability to make decisions regardless of involvement from authority figures.[9] If an adolescent meets these criteria, they are not only cognitively capable of participating in their EOL planning, but it is also likely they will have strong preferences about those plans. This is captured in the results of one longitudinal study, involving patients age 14-21, confirming that adolescents with serious illness understand treatment options and decisions and want to be involved in decisions throughout the course of their illness.[13]

While serious illness may jolt an adolescent into mature and difficult conversations, prognostic uncertainty in pediatrics can complicate the decision-making journey.[16] Other factors working against adolescent autonomy in this arena include the notion that adolescents may be inclined to choose more non-beneficial interventions than their adult counterparts because of having fewer life experiences; a slowed maturation process due to chronic and life-limiting illnesses and physical, cognitive, and emotional regression due to prolonged illness.[17,18,9] Terminally ill teens also face many personal and developmental setbacks. Their puberty may be stunted, while their peers continue to develop.[10] Treatment may result in significant changes to physical appearance, including hair loss, swelling, and exacerbated acne.[10] And chronic illness interferes with the kind of life experiences—such as school, social activities, athletics, and interpersonal relationships—that build the foundation for independence, self-confidence, and social functioning.[10] This isolation effect can be intensified by (understandably) concerned and overprotective parents, and the child's "learned passivity".[10]

III. Engaging Adolescents in End of Life Decision-Making: How Narrative Makes Meaning of an Altered Life Course

a. The Why: Immeasurable Benefits

Adolescents have a distinct illness experience, wholly separate from that of a small child or mature adult. Their accelerated understanding of mortality and their desire for making independent decisions must be balanced with their developmental limitations. Adolescents should be included in EOL discussions as much as possible, in a developmentally appropriate manner.[19,17] Supporting an adolescent's participation in EOL discussions respects their emerging autonomy, and families play a crucial role that process.[18,10] This confers a sense of independence, control, and even liberation.[18] Not only does this process allow adolescents to express their preferences, say goodbyes, participate in ceremony planning and legacy-building, it also pertains to the clinical treatment of the patient and facilitates comprehensive care.[9] Avoiding discussions about death may only make the dying process more distressing for the adolescent, leading to feelings of isolation and exclusion.[20]

Evidence suggests that adolescents are more comfortable discussing EOL issues than we might expect and are giving thought to EOL decision-making.[21] In a study conducted among adolescents ranging in age from 13-21 (25 healthy adolescents, and 25 chronically ill adolescents) 96% of chronically ill adolescents and 88% of healthy adolescents endorsed a desire to participate in EOL decision-making.[21] In another study, 107 adolescents were surveyed about treatment options (i.e. surgery, CPR, dialysis, feeding tubes, ventilator support, and pain medication) in the context of an irreversible coma.[17] Notably, more than 62% reported “comfort with death and dying” and most of them were comfortable talking about EOL decisions.[17] Their decisions were driven by concerns about pain (70.8%), the impact on their family’s finances (64.2%), and the emotional effect on their family (93.4%).[17] In a family-focused advance care planning study involving 17 adolescent/family dyads, more than 90% valued “being free from pain, being at peace spiritually, honest answers from my doctor, understanding my treatment choices, and being able to stay in my own home.”[22] Despite these expressed preferences, most adolescents in the study had not heard of hospice.[22]

Adolescent patients benefit from the process of EOL planning in myriad ways: they report experiencing positive emotions following the discussions; the process demands transparency from physicians; adolescents are taken seriously by their parents and caregivers; and they can explore where and how they want to live out their lives.[16, 9] Medical providers are also beneficiaries in this process. They receive clear guidance, have certainty about the patient’s preferences, and may see improved treatment compliance because the patient actively participated in creating the plan of care.[9] The process gives clinicians a platform for dispelling misconceptions and misunderstandings about the dying process, and medical providers can use this to build rapport with the patient and family.[20]

Engaging adolescents in this process also confers significant benefit to the parents of the dying adolescent. In one study, parents reported a sense of relief after learning about their child’s preferences.[13] Parents, who inevitably must continue making decisions for their children over the course of their child’s illness, can “make informed decisions, alleviate distress, avoid decisional regret, and perhaps provide the patient’s quality of life by respecting their religious, cultural, and familial values and beliefs.”[20] Narrative can and should serve as the framework for this cooperative decision-making process.

b. The How: Narrativity

Narrative is so essential to the comprehension of self that people begin creating narrative identity as young children.[23,24] “We live by stories, and they’re what give sense to our lives.”[25] Complications to this sense of narrative identity arise when we start with certain expectations about the trajectory of our lives, and suddenly something alters that life course, what Aristotle calls *peripeteia*. [25] When a medical diagnosis is the culprit of that unnatural change or truncated trajectory, patients grapple with uncertainty and the disorientation of time. “Living in prognosis severs the idea of a timeline and all the usual ways we orient ourselves in time: age, generation, and stage in assumed lifespan.”[15] The identification of a new sense of self can emerge in the wake of *peripeteia*. Narrative can assist in the development of that new self as demonstrated by research into autobiographical storytelling. Rebecca Kameny observes that the “autobiographical story [is] a tool by which the

narrator, when faced with a disruptive event such as a life-threatening chronic illness, can come to understand what he or she is experiencing.”[26] For example, non-fiction accounts, such as *Chronicling Childhood Cancer: A Collection of Personal Stories by Children and Teens with Cancer*, carve out space for children and young adults to share their cancer story in their own words.[27]

It stands to reason that, based on adolescents’ particular developmental features and strong desire to participate in EOL planning despite having limited autonomy, adolescents with life limiting illness will have a different narrative space—the Adolescent EOL Narrative. Four of the major themes that can be identified in the Adolescent EOL Narrative include: 1) the paradox of emerging autonomy and limited lifespan, 2) intensity of emotions, some natural (young love), others unnatural (watching parents grieve), 3) the desire to have significant, and even adult-like experiences on an accelerated timeline, and 4) preferences around legacy and memory-making that can help support a good death.

Although there are existing narrative forms built around the experience of minors, the Adolescent EOL Narrative is distinct. It does not fit, for example, within the already established Pediatric Rescue Narrative. While both concepts consider the premature disruption of a child’s life story and the notion of “innocent suffering,” the Pediatric Rescue Narrative struggles to acknowledge the death of a child.[28] It “constrains pediatricians by limiting their range of response to illness... making it particularly difficult to treat a child when a cure—a rescue—is impossible.”[28] The Adolescent EOL Narrative, however, enables physicians to shift the focus from curative measures to supporting a meaningful dying process, creating space for conversations about a good death.

The Adolescent EOL Narrative also shares some similarities with narrative methodology for adolescents with chronic (but not terminal) illness. Five key narrative themes emerged in a study involving teens age 15-19 with chronic illness, specifically Crohn’s Disease and juvenile idiopathic arthritis: 1) “walking a different path,” which involved changing plans and embracing new opportunities; 2) “tolerating contradiction,” understanding that health and illness can be intertwined; 3) “changed interface with others,” particularly perceptions of accelerated adulthood and continued childlike features; 4) “locating power” or creating a sense of agency and control over the disease; and 5) “fluid relationship” or understanding that chronic illness is just one element of the person and not the defining feature.[29] Adolescent EOL Narrative has many parallels to that form; however, whereas those with chronic illness may acquire new ways to cope with their disease, manage it, and learn to live through it, adolescents facing early death are learning about how and where they want to die, what they can achieve or experience in a condensed timeline, and what will remain in their absence.

Adolescent EOL Narrative also varies from other adolescent forms of narrative unrelated to illness. In *Narrative Development in Adolescence*, the authors consider narrative construction with parent and grandparent influences, the narrative of troubled and at-risk youth, and themes of young motherhood.[30] These forms of narrative focus on identity development during the transition to adulthood without the confines of illness. The Adolescent EOL Narrative emphasizes the decisions and experiences that must occur more urgently, with the expectation that adulthood will not be achieved.

Our position is not without objections. Critic Angela Woods cautions against creating new and particular forms of narrative. Doing so, she argues “promotes a specific model of the self” and excludes diverse perspectives that do not fit within that form of narrative.[31] Galen Strawson, the philosopher Woods heavily draws upon for her critique, has gone so far as to say that “ethical narrativity” can “needlessly and wrongly distress those who do not fit their model, and are potentially destructive in psychotherapeutic contexts.”[31,32] Strawson has opined that there are people who “are likely to have no particular tendency to see their life in narrative terms” and that these individuals can actually be harmed by the pervasive normative approach to narrative.[32] Not all individuals will conceive of themselves narratively, which is to say that some individuals—Strawson evidently being one—have no “special interest” in their past nor any “great deal of concern” for their future.[32] While avoiding what Woods refers to as “promoting (particular forms of) narrative as *the* mode to human expression” has a relatively straightforward solution, Woods’s reliance on Strawson’s concept of the “episodic self” is considerably more difficult.[31] One simple response might be to concede the point and suggest that part of developing narrative competence is being able to identify those individuals who are not engaged in any particular narrative process. However, this seems *too* simple and not entirely authentic.

Narrativity presupposes a belief in subjective continuity of personal identity over time—a premise Strawson rejects so strongly that he has argued against moral responsibility.[33] Those who rely on narrative in philosophy look to it not solely as a pathway for subjective experience, but as a solution to the Leibniz-ian problem of numerical identity of the self. That is, Galen Strawson at 5 years old does not have the same properties as Galen Strawson at 65 years old. Accordingly, we need some mode by which we can say these two things are actually one and the “same” person. Philosophers such as Daniel Dennett have suggested that the self is the thing that unites the person through time, and that the self operates as a kind of center of narrative gravity, immaterial and abstract.[34] People experience their “sameness” by way of that narrative. It is this point that Strawson refutes when he writes, “it seems clear to me, when I am experiencing or apprehending myself as a self, that the remoter past or future in question is not my past or future, although it is certainly the past or future of GS the human being.”[32]

This position seems worthy of substantial debate, certainly more than this paper can engage in. However, if we are to abandon narrative, there must be something that replaces it, not merely to provide people with a mode of experience, but in order to solve the foundational puzzle. Woods offers alternatives such as metaphor or Carel’s “phenomenological tool kit.”[31] However, she fails to articulate how these alternatives are solutions to the root problem that Strawson is tangling with – continuity of personal identity “from the inside”. Given the depth of discussion necessary to engage fully with Strawson (and thus respond fully to Woods), it may be best at this point to simply say there is disagreement as to whether narrative is the best, much less the only mode of self-understanding and clinicians should be cautious in entering a clinical encounter—fraught with grief, anxiety, fear, anticipation, or confusion—from an overly academic perspective. Still, it seems reasonable that a considerable number of people *do* engage with the world through narrative as any clinician who has taken a patient history can attest.

Finally, Woods has also relied on Strawson to argue that narrative approaches to date have tended towards a monolithic and decidedly Western cultural perspective which has the risk of “shutting down the very diversity of perspectives and forms of self-expression it has long been the task of the humanities, arts and social sciences to argue are vital in the context of medicine and healthcare.”[31] Indeed, *TFIOS* does not represent the experience of all adolescents with life limiting illness, nor is it the intention of these authors to suggest it should be read as such. It is one perspective, viewed through the lens of what must be acknowledged as “white privilege.” Experiencing momentous occasions or having emotionally satisfying relationships may not be the case, or even the desire, for all terminally ill adolescents.

To Woods’ point, Adolescent EOL Narrative should not be used to pigeon-hole teens into having specific encounters, but rather to highlight the larger concept of identity formation and authentic preference, whatever form that may take. Beyond the white, Midwestern Hazel Grace Lancaster—who has distinct cultural status as an Adolescent entitled to certain emotions and experiences—lies thousands of similar and dissimilar teens around the world. It must be noted that the phenomenon of adolescence as a distinct period varies “within a culture and by gender and social class.”[35]

Additionally, Hazel has access to excellent, urban hospital care, whereas rural or socioeconomically disparate teens will experience a much different cancer journey. Beyond geographic location and financial status are additional features of race, ethnicity, class, and immigration status.[36] Understanding how these characteristics impact an adolescent’s EOL experience may be further analyzed by looking at works like *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families* (specifically Appendix D: Cultural Dimensions of Care at Life End for Children and Their Families), and *Culture and Palliative Care: Preferences Communication, Meaning, and Mutual Decision Making*. [36,37] The solution to this problem, therefore, is not to abandon narrative, but to expand cultural perspectives within narrative and to acknowledge that narrative form and voice will certainly differ depending on cultural perspective or background. It is only logical therefore, that in studying these other elements, additional theme of the Adolescent End of Life Narrative may be borne. By no means should *TFIOS* be read as a singular example of adolescent end of life narrative; it is *one* example, and one specific to the demographics of the protagonist.

If we are to understand adolescence as a time of identity exploration and formation, it makes little sense to dismiss narrative as failing to accurately capture one’s existential triviality. After Erik Erikson’s *Identity: Youth and Crisis* was published in 1968, “the process of self-definition and identity formation became normative developmental tasks” for adolescents.[38,39] Dying adolescents, perhaps more than any other patient population, yearn to understand the import of their life and answer the

question: “Who am I?” This is illustrated clearly in *TFIOS* when Hazel reflects on humankind’s desire to be remembered:

Gus told us that he feared oblivion, and I told him that he was fearing something universal and inevitable, and how really, the problem is not suffering itself or oblivion itself but the depraved meaningfulness of these things, the absolutely inhuman nihilism of suffering. I thought of my dad telling me that the universe wants to be noticed. But what we want is to be noticed by the universe, to have the universe give a shit what happens to us – not the collective idea of sentient life but each of us, as individuals.[6]

As *TFIOS* author John Green keenly observed, “I love the intensity teen-agers bring not just to first love but also to the first time you’re grappling with grief, at least as a sovereign being—the first time you’re taking on why people suffer and whether there’s meaning in life, and whether meaning is construed or derived.”[7]

Narrative competence, using fiction and non-fiction, is elemental for learning how to engage adolescents on this level, and “Y.A. novels are peculiarly well suited to consideration of ethical matters.”[7] The most meaningful aspect of Adolescent EOL Narrative is providing a platform for teens to recognize their individual wishes and voice them. EOL discussions often do not occur until a medical crisis arises “because of strong emotions evoked or fear of taking away hope, which contrasts with empirically based research that early palliative care can instill hope, maintain psychological well-being, increase congruence in treatment preferences between patients and their surrogate decision makers, prolong survival, and improve the quality of life and mood among surviving relatives.”[13]

IV. An Example of Adolescent EOL Narrative: *The Fault In Our Stars*

TFIOS offers one perspective on how teenagers grapple with their mortality, prioritize life events, and contemplate their legacy in response to their prognosis. The protagonist in *TFIOS*, 17 year old Hazel, grapples with Stage IV thyroid cancer, with metastasis to the lungs. Her life-limiting illness requires around-the-clock oxygen therapy, and one of Hazel’s distinct features is her oxygen cart and cannula. Some of the most significant markers in her life revolve around hospitalizations. She often harkens back to a near death experience that informs her understanding of her illness and the emotional suffering of her parents. Hazel’s disease has left her socially isolated, away from her high school peers, and constantly under the watchful care of her parents. Her only opportunity for socialization is a pediatric cancer support group, where she meets Augustus (“Gus”), an 18 year-old with a history of osteosarcoma. The two become fast friends and relate on an intellectual and emotional level. Their relationship develops romantically, but the novel takes a sharp turn to reveal that Gus’s cancer has returned and metastasized. Many moments in the book resonate with the four main themes of the Adolescent EOL Narrative. These excerpts demonstrate only a small sampling.

a. Paradox

TFIOS is littered with moments of interplay between the innocence and discovery of adolescence, and the sudden realization that adulthood will never be achieved. Herein lies the first

theme of the Adolescent EOL Narrative: the paradox of emerging autonomy and limited lifespan of a teenager with terminal illness. This concept is succinctly and humorously captured by Hazel when she reflects on her cancer diagnosis coming shortly after her first menstrual cycle:

I told Augustus the broad outline of my miracle: diagnosed with Stage IV thyroid cancer when I was thirteen (I didn't tell him that the diagnosis came three months after I got my first period. Like: Congratulations! You're a woman. Now die.) It was, we were told, incurable.[6]

This tension arises over and over again and is prominently featured between Hazel and Gus as their relationship flourishes and then abruptly ends. Hazel opines:

I missed the future. Obviously I knew even before his recurrence that I'd never grow old with Augustus Waters. But thinking about Lidewij and her boyfriend, I felt robbed.[6]

Adolescents similarly situated to Hazel or Gus will undoubtedly feel frustrated and cheated out of life's richness. As self-identify and relationships come into focus, the adolescent's life limiting illness tears it down. While their peers are planning for college, anticipating moving away from home, and envisioning careers, these adolescents know they may never achieve complete and unencumbered independence.

b. Intensity of Emotions

Throughout *TFIOS*, Hazel constantly struggles with the impact her illness has on her family. As Hazel begins to fall in love with Gus, she envisions the emotional harm he will experience when she dies. She also contemplates the suffering her parents will endure, but simultaneously recognizes there is nothing she can do to protect them from that pain. This demonstrates the second element of Adolescent EOL Narrative. The intensity of emotions—some that are a natural part of adolescence and others that are a byproduct of being a teenager facing death—are real feelings that cannot be ignored.

"Honey," my mom said. "What's wrong?" "I'm like. Like. I'm like a grenade, Mom. I'm a grenade and at some point I'm going to blow up and I would like to minimize the casualties, okay?" My dad tilted his head a little to the side, like a scolded puppy. "I'm a grenade" I said again. "I just want to stay away from people and read books and think and be with you guys because there's nothing I can do about hurting you; you're too invested, so just please let me do that, okay? I'm not depressed. I don't need to get out more. And I can't be a regular teenager because I'm a grenade." [6]

Unfairly, adolescents with life limiting illness will observe the sorrow of their parents and siblings as family members grieve their anticipated loss. This heavy emotional burden is a significant part of the child's thought process as it relates to dying.[17] Over the course of *TFIOS*, Hazel's parents cater to her every need, making Hazel feel uneasy about what their future will hold when she dies. Hazel's anxieties are somewhat allayed when she learns her mom has been quietly pursuing a degree in social work to help other families. Hazel bears the burden of her own suffering and of her parents' emotional turmoil.

c. Significant Experiences

In the Adolescent EOL Narrative, like in *TFIOS*, a reader can expect to identify a survival timeline that allows the adolescent to participate in significant experiences, “wish trips, graduation, school dances, or other social functions.”[10] Hazel and Gus reflect on their travels to Amsterdam and its significance:

We lay there together as he told me they’d started palliative chemo, but he gave it up to go to Amsterdam, even though his parents were furious. They’d tried to stop him right up until that morning, when I heard him screaming that his body belonged to him. “We could have rescheduled,” I said. “No, we couldn’t have,” he answered. “Anyway, it wasn’t working. I could tell it wasn’t working, you know?”[6]

Older adolescents can find important meaning in their romantic and sexual relationships with a significant other.[10] Young love in this narrative space may show teens who are awkward and also completely consumed by romance. When appropriate, these relationships should be respected by clinicians and seen as an opportunity for that adolescent to experience mature physical and emotional intimacy before dying.[10] In *TFIOS*, Hazel and Gus, both virgins, experience their first sexual encounter together. Their romantic experience provides them with a sense of normalcy and discovery. In some ways, her romance with Gus allows Hazel to reconcile her suffering:

And then we were kissing. My hand let go of the oxygen cart and I reached up for his neck, he pulled me up by my waist onto my tiptoes. As his parted lips met mine, I started to feel breathless in a new and fascinating way. The space around us evaporated, and for a weird moment I really liked my body; this cancer-ruined thing I’d spent years dragging around suddenly seemed worth the struggle, worth the chest tubes and the PICC lines and the ceaseless bodily betrayal of the tumors.[6]

These experiences may be top of mind for the terminally ill adolescent. Adults can acknowledge and appropriately support the accomplishment of these experiences, and in doing so may engender trust and create space for other, more difficult EOL discussions.

d. Legacy

The final element of the Adolescent EOL Narrative is the adolescent’s emphasis on leaving a legacy. Gus desperately seeks to know how he will be remembered when he dies. When he learns that his osteosarcoma has recurred and metastasized, he asks his friends to eulogize him while he’s still alive. This is an essential part of Gus’s EOL process. He yearns to know that his life made an impact on others. He sardonically comments:

“I’m hopeful I’ll get to attend as a ghost, but just to make sure, I thought I’d—well, not to put you on the spot, but I just this afternoon thought I could arrange a prefuneral, and I figured since I’m in reasonably good spirits, there’s no time like the present.”[6]

In this moment, Gus, Hazel, and Isaac share tears and witty banter. Gus even chimes in to revise Isaac’s remarks. This experience played a significant role in Gus’s dying process. Hazel, often more existential in her reflections, shows subtle signs that she, too, worries about how she will be remembered. When considering the death of another teenager, Hazel observes:

She seemed to be mostly a professional sick person, like me, which made me worry that when I died they'd have nothing to say about me except that I fought heroically, as if the only thing I'd ever done was Have Cancer. [6]

Adolescent EOL Narrative acknowledges that, while not all teens have the same preferences, they all have authentic wishes, hopes, and fears that deserve to be acknowledged and honored.

V. Using an Adolescent Planning Guide to Facilitate Adolescent Narration

Gaining narrative competence allows medical providers to accompany dying adolescents through the journey of creating their new story. "Narration is an activity by which the speaker reconstructs and reinterprets past, present and future events." [26] *TFIOS* is particularly accessible and relatable for teens. And while it can be difficult for people to contextualize their own experiences, they can rely on narrative to provide a sense of community, relatability, and even normalcy. Adolescent may align with a fictional character as a point of reference when considering their own EOL wishes. To that end, guided readings or movie viewings of *TFIOS* may give adolescents permission to think about and express their otherwise privately-held, complex feelings. Designed and developed by researchers at the Pediatric Oncology Branch, National Cancer Institute, and the National Institutes of Mental Health at the National Institutes of Health, adolescent planning guide Voicing My CHOICES™ (VMC) gives adolescents an opportunity to narrate their EOL experience. [8] VMC is a developmentally appropriate tool, designed linguistically and aesthetically for teens.

Research shows that, when thinking about EOL decisions, adolescents want medical terminology to be clearly explained; extensive opportunities to talk about pain management; and to know how their belongings will be shared among friends and family. [40] VMC gives adolescents a chance to specifically talk about their legacy and how they want to be celebrated and mourned. It includes space to talk about forgiveness, more opportunities to reference friends (not just family), and additional prompts to express preferences about music and food. [20] The document allows an adolescent to say "if friends are coming to visit, please dress me, comb my hair, and do whatever else is needed to help make me look like myself." [8] It affords autonomy and dignity among a young population that may otherwise feel powerless.

An example of how adolescents can use VMC to create a new narrative is beautifully captured in *The New York Times* piece "Teenagers Face Death, on Their Terms." [41] In it, the reader sees a copy of 17 year old Ashleigh McHale's VMC document. In alternating hot pink and bright blue pen, McHale notes that she wants to be dressed in "cute jeans, white shirt (plain), cowgirl boots" for her services. [41] At her funeral, she wants "roses-red, black balloons with hot pink stars or hearts to be released, and contributions to help family." [41] She also checks the box next to "research protocol autopsy." [41] She captures elements of legacy in this planning guide, striving to financially help the family she will leave behind and offering her embattled body for scientific research. Although VMC is a template document, it can guide adolescents, with help from medical providers and family, to write their new story.

VI. Conclusion

Narrative competence with adolescent EOL can be a valuable skill for medical providers, parents helping terminally ill adolescents, and for the adolescents themselves. *TFIOS* can be examined and used as a means for understanding the unique struggles of dying adolescents. Undoubtedly, the contextual features of *TFIOS* elucidate certain thematic structure, and learners are encouraged to explore diverse works related to this subject matter. Despite its limitations, *TFIOS* provides insight into the conflict between emerging autonomy and dependence, and demonstrates that teens have a specific and authentic thought process about EOL preferences. Four major themes of Adolescent EOL Narrative—1) the paradox of emerging autonomy and limited lifespan, 2) intensity of emotions, 3) the desire to have significant, sometimes expedited experiences, and 4) preferences around legacy—can serve as guideposts for adults and adolescents to organize their thoughts and make sense of an abridged life journey. Other adolescent EOL fiction and non-fiction, with different author and character perspectives, will almost certainly uncover additional themes that take shape in the context of varied developmental, cultural, spiritual, and socioeconomic features. Indeed, this paper is an invitation to explore Adolescent End of Life Narrative, not to restrict or limit it.

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