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Amplifying Awareness: Narrative Rationality in the Discourse of Childhood Cancer

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Abstract

This paper looks into the complex psychological and economic effects of pediatric cancer on families. The paper has devastating realism as it draws on personal experience, as illustrated by the author's brother, Dylan, dying of brain cancer. Dylan's shortened life serves as a harsh reminder of the need to address this serious problem. The paper delves into the power of Aristotle's persuasion model, specifically looking at the concepts of ethos, pathos, and logos. This persuasion model ties into narrative rationality in the paper and looks at how a story's coherence and fidelity can make a large impact on persuasion and convincing an audience. Can storytelling make a difference in the fight against cancer? This paper aims to generate a meaningful discussion about childhood cancer by combining academic writing with personal narratives. It emphasizes the power of storytelling to shape perceptions and motivate action. This paper seeks to remember the children who have died as well as push for a change in the fight against cancer. The paper ends with a personal story of *Miles the Brave* that the author encourages others to share in the hope for a change.

Keywords: Childhood Cancer, Narrative Rationality, Storytelling, Communication Advocacy, Persuasion.

Introduction

A rhetorical device is a strategy or style of language employed by a speaker or author to elicit a certain emotion from the listener or reader and persuade them to think in a certain manner. I know what you're thinking: this is going to be a dull paper on rhetorical techniques. But don't worry, it's also a wonderfully interactive paper! Starting with a pop quiz. What rhetorical tactic comes to mind when I utter phrases like "deafening silence" or "jumbo shrimp"? That's correct, an oxymoron! However, this paper is not about oxymorons, as much as I wish it was. I came upon a publication that discussed the psychological health of family members who had a kid with cancer. A 12-year-old boy who was questioned about his younger sister's sickness remarked, 'The two words childhood and cancer have an oxymoron-like quality to them.' However, pediatric cancer is a global epidemic that has affected millions of people.

I consider myself an expert on the subject because it has impacted my family and me. My brother was 10 years old when he started to get severe headaches. My mom took him to many Doctors and they all told her it was just a concussion from baseball season. My mother knew it was more than that and kept advocating that something was wrong. About a week later he was diagnosed with cancer. He loved football, Jesus, and Legos. He had a Diffuse Intrinsic Pontine Glioma, which is otherwise known as brain cancer. With exactly two and a half months to live following the diagnosis, my family's lives were irrevocably transformed. I know I'm not alone in this. Everyone seems to know someone who has had cancer, whether a child or not. It is a global epidemic. With the aid of narrative reason, we can raise awareness and advocate for children with cancer.

The Cancer Crisis

Childhood cancer is defined as cancer that occurs in someone between the ages of 0-19. According to the American Cancer Society, "About 10,500 kids are diagnosed in the US every year". According to WHO, of those 10,500 kids, only 80 percent of them will survive it. And that's if they are lucky enough to live in a high-income or medically advanced country such as the United States. I'll do the math for you, 20% of 10,500 is 2,100 children who will die due to childhood cancer each year. It is the leading cause of

death by disease for children. According to the NCHS Data Brief, "In 2021, brain cancer was the most common type of cancer-causing death in youth" followed by leukemia and bone cancers. Despite these staggering figures, there is still a significant shortage of money and research being conducted. Every year, thousands of children die, yet the issue is routinely overlooked.

This has far-reaching consequences, particularly for the families and communities that witness young children fighting a horrific battle. Childhood cancer has a profound financial and psychological impact on patients and their families. For example, my parents and I chose to go to therapy, and the grief is still something we deal with to this day. Every single event or holiday feels a bit less wonderful and joyful since cancer stole it from us. Vicki Harrison expressed it best: "Grief is like the ocean; it comes in waves ebbing and flowing. Sometimes the water is calm, and sometimes it is overwhelming. All we can do is learn to swim."

The European Journal of Cancer Care published a study on the psychological consequences on families who have a loved one with pediatric cancer. This study found that present "psychological support services are inadequate to meet the needs of families." Nearly all participants in the research thought that there should have been more alternatives available and that it would have helped them process feelings like anger, guilt, and loss.

Sophie Rex Christensen carried out another research study that looked at how a family dynamic changes when a kid is diagnosed with cancer. Christensen explains a concept coined as 'shuttling'. According to the author, "shuttling between the well-known and the changed or being in a situation with both familiar and new aspects." Shuttling causes several vulnerabilities in the family's foundation. Every family experiences varying degrees of change and shuttling. Christensen's study revealed that four elements influence how effectively a family can handle change: "the diagnosis and prognosis; the course of the disease, including duration of treatment or hospitalizations, and separation from the remaining family; the child's current state, including symptoms, side effects, intensive treatments, hospitalizations, and their current risk of death or relapses; and whether previous and current needs have been met." Christensen finds that these changes "are primarily negative and impair the quality of life for all the family."

It is important to acknowledge that the psychological effect, particularly on parents, can be impacted by financial factors. The medical expenditures are staggering and could take years to pay off. According to the National Children's Cancer Society, "the average cost associated with childhood cancer is a startling \$833,000." I know that my parents had to declare bankruptcy because of my brother's medical bills, even though he had only been sick for two months.

Wiley Journal published a study in 2019 called "The Impact of Childhood Cancer on Parents' Socio-Economic Situation." The research digs deeply into the economics of parents who have cancer-stricken children throughout the world. It sheds light on how the financial burden on families in low-income nations such as Asia and Africa is enormous, and how they frequently choose not to receive treatment for their children. The report states that in the United States "two-thirds of parents reported debts because of the child's disease." The report makes no mention of financial considerations for terminally ill children. If the child dies from the sickness, the family must additionally cover the costs of a funeral, a coffin or urn, a gravestone, and so on.

Persuasion and Narrative Rationality

Narrative rationality is determined by the coherence and fidelity of our stories. To understand narrative coherence and fidelity it is important to understand narrative rationality. It is an idea stemming from the narrative paradigm. The narrative paradigm views people as storytellers, who make decisions based on "good" reasoning. That reasoning is based on history, culture, and characters that are commonly known from stories. The narrative paradigm views the world as a set of stories we choose to create or recreate. Ultimately the narrative paradigm is determined by the fidelity and coherence of stories. Coherence is any content that helps you better understand a story. Coherence can help the audience answer questions such as 'Does the story make sense?' It is the internal consistency of a story. At the same time, fidelity is the credibility and relatability of the story. Fidelity can help the audience answer questions such as 'Could that actually happen?'

When looking at narrative rationality as a means of persuasion, it also ties into Kenneth Burke's dramatistic pentad. Kenneth Burke's Dramatic Pentad is an example of

studying human behavior and motivation, especially regarding communication and rhetoric. The Pentad consists of five major components: the act, the scene, the agent, the agency, and the purpose. Burke thought that by examining how these five factors interact and overlap in certain situations, we can gain a better understanding of the motivations, meanings, and dynamics of human action and communication. Christopher Rideout states in Storytelling, Narrative Rationality, and Legal Persuasion, "The way in which a story is told will have considerable bearing on its perceived credibility regardless of the actual truth status of the story." Meaning that the five parts of Burke's pentad will also ultimately determine the way an audience agrees or disagrees with what is being said to them. When we are trying to persuade our audience all five of those things must match up, it supports the coherence of our story. In the Rideout article, the researcher, Jackson, divides coherence into two parts, internal and external. Jackson explains that internal coherence may leave facts out, or not bring up any of the counterarguments which makes it weak when other people look deeper into your story. In contrast, the external coherence looks at the 'story' from many angles to get the full picture. When you think more about it from the persuasive point of view, external coherence would mean using expert testimonials throughout your speech to help show the argument is not just your opinion.

Internal and external coherence talk about facts, and counterarguments, whereas fidelity is more so objective. Jackson later states in the same article that narrative fidelity is "a matter of assessing the substantive worth of a story, but not in terms of its appeal to abstract universals like the truth, and not in terms of its ability to translate into formal, logical propositions about social reality." This means that fidelity is basically how the story made you feel. The opposite of the logical feeling that comes with coherence. Both coherence and fidelity are important concepts if you are going to be successful in persuading your audience. Ultimately narrative rationality is an important concept to understand because coherence and fidelity are crucial to use if you want to persuade people and have your story or argument be "bulletproof" so to speak.

The three components that makeup Aristotle's persuasion model, ethos, logos, and pathos, can be useful in building a strong argument. Logos is the use of logic or reason to convince an audience. For example, a doctor explains the reasons why you

should try a new medication. Ethos is the application of ethics and reputation to persuade others. For example, many TED lectures begin with a fact that establishes the speaker's credibility, such as identifying their career, or experience in a particular field. If their lecture is on heart failure, mentioning that they are a cardiologist will increase their credibility and, as a result, show their ethos. Pathos occurs when you persuade someone with their emotions. St. Jude's television ads are a fantastic illustration of this. They display videos of sick children that show how much they are suffering and then seek donations to support the children and their families with healthcare expenditures. When considering narrative rationality and selecting how to present a story that will persuade others, it is critical to use these three components whenever feasible.

Miles the Brave

Scott Valley California. The population is around 5,600 people, dispersed across 28 miles of hay and cattle ranches. I was lucky to grow up in this beautiful valley and call it home. It's the type of little town where you wave to every car that passes by and greet everyone you see at the supermarket. Miles John Isbell was also a member of this community. He was born on April 18, 2011. This was just four months before my brother Dylan died of a brain tumor. Fast-forward eleven years, Miles dies of Medulloblastoma, a type of brain cancer. Two eleven-year-old boys, eleven years apart, succumbed to childhood cancer.

Miles had the most kind and caring heart. He had a smile that made you want to smile, which is most likely where the term #smilesformiles originated throughout his two-year fight. #Milesthebrave was also a popular statement and one that was not an understatement. Miles had surgery, chemotherapy, and blood transfusions, and even participated in an experimental trial. He fought a long and difficult battle, yet he never gave up and was constantly smiling. Miles was a warrior, a brother, a son, a grandson, a cousin, a friend, and much more. He made a big impression everywhere he went. He sang classic 80s songs loudly, ran in several races, participated in 4H, was a natural leader, and wanted to help other children like himself.

Living in our little valley has many advantages, but it is quite secluded. The closest pediatric cancer oncologists are in San Francisco or Portland, which are almost

six hours away. Miles and his family traveled extensively throughout the course of his treatment. Miles was devoted to helping build the new Olsrud Family Women's and Children's Hospital in Medford, Oregon. He was looking forward to the new institution because of the benefits it would provide for children like himself in the future. He and his brother gave thousands of dollars from the proceeds of their 4H animals, inspiring hundreds of others, including their friends, to follow suit. As the Miracle Kid, he helped generate more than \$3 million in one night for this cause. Miles' family recently attended the ribbon-cutting event for the new facility, which features a room named in Miles' honor.

Miles, like my brother, adored Legos. Legos are tiny plastic blocks. A common children's toy. They were only children. There is so much to say about our valley boys... however, no words will ever be sufficient. They deserved better. They deserved a future. As my time as a college student concludes, I am constantly reminded that Miles and Dylan will never have the opportunity to attend college. They did not even complete middle school. Cancer took so much from them and their families. This paper cannot fix that.

Childhood cancer is an epidemic. It is not going anywhere on its own. We say that our children are our future, yet we are doing nothing to ensure that our children have a future. We all have a responsibility to share these children's narratives. To raise awareness, wear yellow ribbons, and say their names. Simply share a story. "Their laughter will make your heart melt. Their strength will make a grown person cry. If you ever see a child fight cancer, it will change your life forever." -Unknown

GalleryDylan James Frick















Miles John Isbell











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Learning Outcomes of Communication

LOC #2: Employ Communication Theories, Perspectives, Principles, and Concepts

LOC #4: Create Messages Appropriate to the Audience, Purpose, and Context

LOC #6: Demonstrate the Ability to Accomplish Communicative Goals

LOC #9: Influence Public Discourse