

# **The Stories They Tell**

*How Different Children's Hospitals are  
Using Patient Stories on their Websites*

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## About the Author

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During his tenure with Lyngblomsten and the Diocese of New Ulm, Sam has interviewed hundreds of individuals for dozens upon dozens of pieces, from newspaper articles and blog posts to press releases and videos. Not surprisingly, he has a passion for storytelling—which is what inspired him to pursue this topic for his capstone research project.

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## **Executive Summary**

Children's hospitals provide much-needed services to infants, toddlers, adolescents, and teenagers. What started as one hospital in Philadelphia in 1855 (Mahnke, 2000, p. 709) has grown to more than 200 institutions in 47 states in 2018 (Children's Hospital Association, n.d.). Not surprisingly, these hospitals are competing for patients and, thus, have deployed a variety of communications strategies to influence potential customers.

One tool they're using is their websites, and more specifically, patient stories they publish on their websites. Human beings believe in the persuasive power of stories, so it's understandable that children's hospitals are using them to advance their objectives. Yet no research has examined the content of these hospitals' stories or their effectiveness.

This project seeks to address this research gap by asking the question, "What is the relationship between different children's hospitals and how they use patient stories on their websites?" More specifically, the question seeks to address what narrative elements and media channels are commonly being employed in these stories, how prominent these stories are on hospital websites, and ways that hospitals are using them to differentiate themselves from one another.

Two content analyses were conducted. One examined narrative elements present in 93 patient stories from six children's hospital websites, and the other examined the prominence of patient stories on these hospitals' websites. In addition, interviews were held with five officials from four children's hospitals. Findings from these methods revealed the following:

- Children's hospitals are using patient stories to reach their target audiences. These target audiences influence how the stories are crafted and what narrative elements are featured.

- Children's hospitals are using common messages and ways of describing children in their patient stories. The researcher did not discover new thematic archetypes that are unique to these patient stories.
- Children's hospitals with well-known brands and those that provide specialized services are using particular narrative elements in the stories they publish, which could help them stand out from the competition.
- Children's hospitals are looking to publish more stories in video format, and they're open to publishing stories narrated from the first-person perspective. But these variations must align with the hospital's overall communications goals, and there are practical limitations officials will encounter in pursuing them.
- Children's hospitals are publishing patient stories on their websites in a common repository and on disease-specific web pages. The prominence of stories on a hospital's homepage may not be the best measure as to whether they are reaching target audiences.
- Children's hospitals should publish stories that better address the needs of one of their key audiences: current patients.

The research methods produced a wealth of data; however, one cannot generalize the findings to all children's hospitals due to the sample sizes for the content analyses and qualitative nature of the interviews. Future areas of research involve expanding the sample sizes and conducting experiments that could suggest a correlation between narrative elements present in patient stories and the attitudes, beliefs, and intentions of the hospitals' target audiences.

These findings informed the following recommendations on how communicators can best craft and publish patient stories on children's hospital websites:

1. Know your audience.

2. Make sure your stories' key messages address what your audiences need.
3. Don't shy away from stories that highlight an illness' challenges, as these stories likely will appeal to patients and families in the midst of treatment.
4. Focus on what makes your hospital unique—and then deploy narrative elements in your stories that reinforce this.
5. Let kids be kids by having their personalities shine through your stories.
6. Be open to experimenting with different media channels and narrative elements, but know that human factors likely will limit your ability to do so.
7. Use your hospital's digital team to place your patient stories where they'll be picked up by your audiences.

## Introduction

Generations from now, what sources will historians use to chronicle what life was like for human beings in the 21st century? Lists of laws enacted by local and national governments? Zettabytes of digital data housed on servers across the globe?

They'll likely turn to these sources, and with good reason. But according to 20th-century American author Flannery O'Connor, there's another repository of information they shouldn't overlook.

Stories.

"There is a certain embarrassment about being a storyteller in these times when stories are considered not quite as satisfying as statements and statements not quite as satisfying as statistics; but in the long run, a people is known, not by its statements or its statistics, but by the stories it tells" (O'Connor, 1969, p. 192).

Only recently has the field of mass communications begun to explore the persuasive power of stories (or *narratives* as they're commonly referred to in the literature) (Perloff, 2014, p. 270; Green & Brock, 2000). Scholars have examined what role vividness effects (Baesler & Burgoon, 1994; Taylor & Thompson, 1982), transportation (Green & Brock, 2000), and identification (Dillard & Main, 2013) may play in one story being more persuasive than another. To date, their research has yielded inconclusive results.

Yet despite this, scholars continue to defend the value of stories. "The promise and appeal of narrative," Kreuter et al. write (2007), "lies in its familiarity as a basic mode of human interaction" (p. 222). Human beings are "*homo narrans*, the species distinguished by its ability and predisposition to tell stories" (Sharf & Vanderford, 2003, p. 14). These stories can "give order to human experience and ... induce others to dwell in them to establish ways of living in



common” (Fisher, 1984, p. 6). Indeed, as Green and Brock (2000) astutely observe, novels, tabloid articles, and music lyrics—all of them narratives, in a way—continue to capture individuals’ attention more intently than do rhetorically oriented sermons, editorials, and billboard advertisements (p. 701).

No wonder, then, that organizations of all shapes and sizes are turning to narratives as a tool to achieve their communication objectives. One industry that’s doing so is health care. The American Medical Association reports that health spending in the U.S. reached \$3.3 trillion in 2016, an increase of 4.3 percent from the year before (Rama, 2018, p. 1). And the Centers for Medicare & Medicaid Services projects that national health spending will reach \$5.7 trillion by 2026 (Centers for Medicare, 2018). Health care officials know that their market is growing—the challenge they face is convincing potential patients to choose their organization.

This research project shall examine how one type of health care organization—children’s hospitals—is using narratives to communicate with the public. Specifically, it will look at how children’s hospitals are using patient stories on their websites. If, as Huerta, Walker, and Ford (2016) suggest, websites are a “critical” tool that children’s hospitals can use to maintain a relationship with patients (Discussion section, para. 2), then crafting and presenting high-quality patient stories is essential. This project’s research question is the following:

**RQ1. What is the relationship between different children’s hospitals and how they use patient stories on their websites?**

The literature review that follows will situate this research question within the field of mass communications, addressing the following items:

1. Defining a children’s hospital,
2. Describing what research has been conducted on children’s hospital websites,

3. Defining a patient story, and
4. Defining how children's hospitals are using patient stories on their websites.

## **Literature Review**

### **What is a children's hospital?**

The American Hospital Association (n.d.) defines a hospital as an institution whose “primary function ... is to provide patient services, diagnostic and therapeutic, for particular or general medical conditions” (p. 1). Care is provided by medical staff (licensed physicians, registered nurses) and can include diagnostic x-ray, clinical laboratory, and operating room services (American Hospital Association, n.d., pp. 1, 2).

A children's hospital, as its name suggests, provides care to children from birth through 17 years. These hospitals emerged in the mid-1800s across Europe as medical personnel recognized that children “were ... not simply small adults,” but rather constituted “a group with special medical needs” due to its members’ “unique physiology, biochemistry, and pathology” (Mahnke, 2000, p. 711).

In the United States, the first freestanding children's hospital to open its doors was the Children's Hospital of Philadelphia, which did so on November 23, 1855 (Mahnke, 2000, p. 709). By 2004, the number of children's hospitals had grown to approximately 275, including institutions that were freestanding, ones that were located within larger hospitals, and others that provided specialized services (Schneider & Macey, 2004, p. 17). This research project's definition of children's hospitals includes all three types.

### **Current research on children's hospital websites**

Of the eight Minnesota hospitals listed in the online directory of the Children's Hospital Association, all of them have websites—a fact that likely holds true for the other hospitals (more than 200 of them) on the list (Children's Hospital Association, n.d.). This state of affairs isn't

surprising. With 77 percent of Americans online daily, businesses—including children’s hospitals—need to have a presence there to reach them (Perrin, 2016).

These daily users aren’t simply shopping on Amazon and accessing their social media accounts. As early as 2004, researchers had noticed the increasing number of individuals who were using websites to find health information (Kind, Wheeler, Robinson, & Cabana, 2004, Introduction section, para. 2). A decade later, Huerta, Hefner, Ford, McAlearney, and Menachemi (2014) noted that “more than 80% of adults reported using Internet resources to support health care decisions” (Introduction section, para. 1).

Yet despite the importance of the internet for children’s hospitals, few studies have examined the quality of their websites. Kind et al. (2004) describe technical characteristics of 26 children’s hospital websites. And while Huerta et al. (2016) examine 153 websites, they limit their research to identifying how well the sites adhere to Internet usability standards. Neither study notes whether these sites contain patient stories, nor do they measure the stories’ availability (or prominence) on the websites or their narrative elements. This research project will examine these variables.

### **Defining a patient story**

In order to do this, one must first define a patient story. Communications scholars tend to use the term *narrative*, and not *story*, in the literature. For this research project, the two terms will be used interchangeably.

Kreuter et al. (2007) define a narrative “as ‘a representation of connected events and characters that has an identifiable structure, is bounded in space and time, and contains implicit or explicit messages about the topic being addressed’” (p. 222). Tussyadiah, Park, and Fesenmaier (2011) highlight similar elements, noting that narratives have characters, a sequence

of temporally related events, causation, and a plot (p. 68). The plot shows how a story's "sequence of events builds toward climax and resolution" (Kreuter et al., 2007, p. 230).

All narratives are told from a particular *point of view*, which is the "perspective established by an author by means of which the reader is presented with the characters, actions, setting, and events which constitute the narrative" (Stern, 1991, p. 10).

One must also consider a narrative's purpose. In many cases, this is to entertain and provide pleasure to readers and viewers. Works that fall in this category include novels, short stories, movies, and other fictional accounts. But a narrative also can be used by organizations for persuasive purposes. Some of these narratives are fictional—such as soap operas and cartoons whose purpose is "to educate the public about health or social issues"—while others recount the experiences of real-life, historical individuals, such as news stories and case histories found on company websites (Kreuter et al., 2007, p. 222).

Having reviewed various components of narratives, one can now define what a patient story is for this research project. A patient story is defined as *an historical narrative, told from the first- or third-person perspective, that focuses on an ill child.*

***The story is historical.*** Kreuter et al. (2007) include fictional stories (e.g., soap operas, cartoons, dramas) in their examination of cancer-related health care messages (p. 222). For this research project, fictional accounts are not included in the definition of patient stories. The definition only includes stories that describe events experienced by real-life, historical individuals.

***The story is told from the first- or third-person perspective.*** A cursory survey of patient stories on children's hospital websites shows that most of them are told from the third-person perspective. Some, however, are told from the first-person perspective, in which a patient or

other individual provides a direct account of the child's illness and hospital experience. For this research project, both third- and first-person accounts are included in the definition of patient stories.

*The story focusses on an ill child.* For this research project, each patient story should include a sequence of events that focuses on an ill child.

### **How are children's hospitals using patient stories on their websites?**

Having defined children's hospitals and patient stories, one can now examine how the former are using the latter on their websites. One way to consider RQ1's dependent variable (i.e., "how they [children's hospitals] use patient stories on their websites") is through the following questions:

**RQ2. How are children's hospitals crafting patient stories? That is, what narrative elements are they commonly including—if any—in the patient stories they create for their websites?**

**RQ3. How are children's hospitals presenting patient stories on their websites? This includes the placement, or prominence, of the stories on the sites and the media channels used to present the stories.**

And a fourth topic helps clarify the primary research question even further:

**RQ4. What individuals do children's hospitals want to reach through the patient stories they publish on their websites?**

The immediate goal in examining these factors is to identify commonalities among the patient stories and how they are being used—commonalities in their narrative elements, their prominence on the websites, their media channels, and their intended audiences. The secondary goal, however, is more significant. Identifying these patterns (or lack of patterns) will help shape

recommendations for communicators and marketers at children's hospitals. They may not have considered whether they are using patient stories to their full potential, so the recommendations that flow from RQ2, RQ3, and RQ4 will provide them with greater insight.

**RQ2: Narrative elements included in patient stories.**

This research project shall examine four narrative elements present in patient stories, two of which have already been mentioned: characters, point of view, subject matter, and theme.

*Characters.* Characters are “the people who enact the events of the story,” and can include “heroes, villains, victims, and innocent bystanders” (Sharf & Vanderford, 2003, p. 15). For this research project, characters refer to the individuals who are mentioned in a patient story. Each story must include a child who is ill, and other characters likely will include the child's parents or guardians, other family members, and medical staff.

*Point of view.* Identifying a story's point of view (i.e., the person who is narrating the story, regardless as to whether she is the focus of the story) is fairly easy to do, and this shall be done for the patient stories studied in this research project. But why identify a story's point of view at all? Stern (1991) and Frank (1994) provide some clues as to why this may be helpful.

Stern develops a theory as to how a story's point of view might help an advertisement achieve its objectives. She admits it is not supported by empirical research (Stern, 1991, p. 10), but it still provides a helpful framework for why marketers might employ one perspective over another when crafting a patient story.

The third-person perspective, which is used frequently in advertisements, is adept at conveying “information about products or services” due to its widely accepted role as an objective teacher or storyteller (Stern, 1991, pp. 13, 14). First-person accounts, on the other

hand, help humanize organizations because they establish “a personal relationship between the presenter and an audience” (Stern, 1991, p. 12).

Frank (1994) discusses third- and first-person points of view in his examination of illness narratives (first-person accounts of individuals experiencing an illness) (p. 2). “Cultural preference for third-person accounts ... ha[s] more to do with protecting those who do not want to hear too much,” he writes (Frank, 1994, p. 3). With a first-person account, the reader is forced to “confront the ill person as an active subject” instead of as a “mute object” who receives treatment from a physician (Frank, 1994, pp. 3, 6).

Summarizing Stern and Frank’s analyses, by identifying a story’s point of view, one can begin to speculate what effects the story might have on someone who reads it. Does the story seek to educate viewers (a third-person account), or is it more focused on creating an emotional connection with them (a first-person account)? Does it seek to challenge patients’ conceptions about illness or an aspect of health care (a first-person account), or is it content with a “milder” third-person presentation?

***Subject matter.*** For this research project, subject matter refers to a topic that is featured in a story; it does not refer to the characters (or subjects) that are in a story. One framework that has been used to identify different topics in health care stories is the Cancer Control Continuum. In use since the mid-1970s, the continuum identifies “five sequential areas of cancer experience”: prevention, detection, diagnosis, treatment, and survivorship (Abrams, 2017; Kreuter et al., 2007, p. 222). Neither Kreuter et al. (2007) nor Abrams (2017) define these five areas; however, Abrams provides examples of each, which are listed below to help clarify what each area encompasses.

- Prevention: tobacco control, diet, physical activity, and sun protection.



- Detection: mammography, fecal occult blood test, and colonoscopy.
- Diagnosis: shared and informed decision making.
- Treatment: curative treatment, non-curative treatment, symptom management.
- Survivorship: coping and health promotion for survivors.

For this research project, the subject matter of children's hospital patient stories shall be identified.

**Theme.** Tussyadiah et al. (2011) state that “a story must be an organization of events into an intelligible whole such that [the] audience can always capture the ‘thought’ of the story” (p. 68). One element that crystalizes the “thought” of a story is its *theme*. Referred to as a plot or drama by Sharf and Vanderford (2003), theme is “the *meaning* that emerges from how key events and characters’ actions are configured [emphasis added]” (p. 15).

Scholars have identified themes that appear in first-person illness stories (Caputo, 2014, p. 211; Frank, 1994), including humanities professor Anne Hunsaker Hawkins. In her 1993 work *Reconstructing Illness: Studies in Pathography*, Hawkins introduces the term *pathography*, defining it as “a form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death” (p. 1). Despite being written by individuals from different cultures and time periods, pathographies have common thematic elements:

What is striking about pathography is the extent to which these very personal accounts of illness, though highly individualized, tend to be confined to certain repeated themes—themes of an archetypal, mythic nature. Over and over again, the same metaphorical paradigms are repeated in pathographies: the paradigm of regeneration, the idea of illness as a battle, the athletic ideal, the journey into a distant country, and the mythos of healthy-mindedness. (Hawkins, 1993, p. 27)

These five themes<sup>1</sup> shall now be described.

1. *Regeneration.* The regenerative, or rebirth, myth has two components: “the notion that the self is someone transformed and the impression that for this changed self the whole world appears new and different” (Hawkins, 1993, p. 34). This theme is commonly found in pathographies that chronicle heart illnesses (e.g., a heart attack), in which the illness serves “as a turning point around which authors retrospectively interpret their lives ... and prospectively plan the life that lies ahead” (Hawkins, 1993, p. 37).
2. *Illness as a battle.* Commonly found in cancer pathographies, this myth presents medicine as a militaristic battle between disease and patient (Hawkins, 1993, pp. 64, 66). Victory is accomplished through a cure, in which the “beasts” that are diseases “are suppressed, controlled, chained beneath the surface of our ‘healthy’ lives” (Hawkins, 1993, p. 64).
3. *Athletic ideal.* The athletic ideal myth and the battle myth are similar in that they “both share the sense that recovering from an illness is like winning a battle or an athletic contest” (Hawkins, 1993, p. 77). But the athletic ideal myth differs slightly in that it sees illness not as a foe to be conquered, but as a challenge to be overcome (Hawkins, 1993, p. 77). Furthermore, it celebrates “sportsmanlike qualities that our culture generally admires,” things like courage, self-reliance, determination, and humility (Hawkins, 1993, p. 76).

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<sup>1</sup> Another theme Hawkins (1993) identifies focuses on death and dying (pp. 91-124). She writes that pathographies present a variety of views as to what constitutes “the good death,” including the ritual death, a manly death, the transcendent death, and the easy death (Hawkins, 1993, pp. 92, 97, 104, 107, 110). These different accounts exist today because there is an “absence of any central, coherent art of dying” (Hawkins, 1993, p. 96). Because the researcher expects that very few, if any, of the patient stories on children’s hospital websites will have this as a central theme, he will not include it as part of the project.

4. *Journey into a distant country*. The journey myth encompasses “any kind of heroic exploration of the unknown, the dangerous, and the frightening” (Hawkins, 1993, p. 78). Unlike the battle myth, it chronicles the personal transformation patients undergo through their illness experiences (Hawkins, 1993, p. 88).
5. *Healthy-mindedness*. The myth of healthy-mindedness has three defining aspects: healing comes through a patient having a positive attitude, a patient should rely on her body to heal itself, and a patient should be actively involved in her health care decisions (Hawkins, 1993, pp. 125, 128). With healthy-mindedness, patients are empowered and freed from “dependence on a medical system that is too often depersonalizing, bureaucratic, and uncaring” (Hawkins, 1993, p. 128).

While Hawkins derives these mythic themes from book-length autobiographies, the researcher believes they can be applied to the shorter illness narratives under examination in this project. The project seeks to identify which of these themes, if any, are commonly found in children’s patient stories and possibly to expand the literature by identifying new themes that are present.

### **RQ3: Presentation of patient stories on children’s hospital websites.**

In addition to examining what narrative elements are present in patient stories, this research project shall investigate how children’s hospitals are *presenting* these stories on their websites. More specifically, it shall look at how *available*, or *prominent*, the stories are on the websites and the *media channels* used to present them.

*Availability of patient stories on websites*. In 2004, Reilly, Leibrandt, Zonno, Simpson, and Morris noted that health care websites were not as user-friendly as they could be (p. 236). They noted that “website usability occurs as a direct result of providing relevant, accessible, and

up-to-date content” (Reilly et al., 2004, p. 239). This underscores the importance of children’s hospitals making the content they produce—including their patient stories—easily available on their websites.

One page that plays a critical role on a website is the homepage. Thus, this project shall assess how available, or prominent, patient stories are on the homepages of children’s hospital websites.

A resource that provides background on this topic is the website usability guidelines developed by the U.S. Department of Health and Human Services. These guidelines are “intended to provide best practices over a broad range of web design and digital communications issues” (U.S. Department of Health and Human Services, n.d.).

For this research project, special attention is given to Guidelines 5.2 and 5.5. Guideline 5.2 notes that all of a website’s major options should be on the homepage. “Users should not be required to click down to the second or third level to discover the full breadth of options on a Web site,” the guideline states (U.S. Department of Health and Human Services, n.d.). Furthermore, Guideline 5.5 specifies that one should “limit the amount of prose text on the homepage”—suggesting that a text-based patient story should not appear in its entirety on the homepage (U.S. Department of Health and Human Services, n.d.). Thus, this research project shall examine whether patient stories are mentioned on the website’s homepage or on any second-level page (i.e., a page one click down from the homepage).

***Media channels used to present patient stories.*** Communicators can present patient stories online using a number of media channels, including text-based articles, photographs, audio files, and videos. It is important for communicators at children’s hospitals to be aware of these options for several reasons. First, individuals’ online habits are changing. According to the

Pew Research Center, 63 percent of U.S. adults were watching videos online in 2014, an increase from 52 percent in 2009 (Olmstead, 2014). As this trend likely continues to increase, communicators will want to assess how they are currently presenting patient stories and whether these media channels are attractive to website visitors.

Second, media channels may have different effects on individuals depending on the *richness* of the media. The idea of *media richness* was proposed by Richard Daft and Robert Lengel. “Media,” they write, “can be characterized as high or low in ‘richness’ based on their capacity to facilitate shared meaning” (Daft, Lengel, & Trevino, 1986, p. 358). Four factors determine the richness of a media channel, which are feedback, multiple cues, language variety, and personal focus (Daft, Lengel, & Trevino, 1986, p. 358). As an example, a video featuring a patient testimonial would be richer than the same testimonial transcribed and presented in a text-based article. This is because the patient’s comments in the video “may be perceived as natural, comparable to how one would communicate in a face-to-face context, which is not as apparent in static text-based media” (Frasca & Edwards, 2017, p. 127). In summary, scholars have noted that “face-to-face ... communication is considered richest, followed by video, then audio only, then text only (Adams, Morris, & Van Scotter, 1999)” (Allen, Van Scotter, & Otonda, 2004, p. 149).

Applied to the content on children’s hospitals websites, this theory suggests that richer media (e.g., videos, podcasts) could have a greater impact on website visitors than leaner media (e.g., text-based articles). Allen et al. (2004) suggest this in their examination of the persuasiveness of employee recruitment messages. “By creating a stronger sense of social presence and personal focus, richer media may also be able to create a more positive affective state in the receiver,” which “may influence both the accessibility of information in the

receiver's memory and the nature of the decision process (Ajzen, 2001)" (Allen et al., 2004, p. 148).

While this research project will not examine the relationship between a patient story's media channel and its persuasiveness, it will note what media channels (text-based article, photographs, videos, or other media) are currently being used to present patient stories on children's hospital websites.

#### **RQ4: Persons that children's hospitals want their patient stories to reach**

Another factor that likely influences how children's hospitals use patient stories on their websites is the persons they want the stories to reach. In an examination of 100 hospital websites, Randeree and Rao (2004) identify both patients and health professionals as potential users of a hospital website (p. 33). "The goal of the website is to provide information of value to the user, either a patient or healthcare professional," they note (Randeree & Rao, 2004, p. 36). These visitors likely use the hospital websites for "information, research, and education" (Randeree & Rao, 2004, p. 33). This research project shall investigate whom children's hospitals want to reach through their website's patient stories.

# Content Analysis

## Introduction

In order to assess how children's hospitals are currently using patient stories on their websites, the researcher conducted two content analyses. As Wimmer and Dominick (2014) note, this research method is "an efficient way to investigate the content of the media" and can be used to describe how organizations "frame general and specific issues" (pp. 159, 162).

Two content analyses were conducted, each one surveying material from six children's hospital websites. The researcher chose hospitals with locations in the Midwest in order to focus on a particular geographic region. Four of the hospitals had their headquarters in Minnesota, one had a facility in Minnesota, and one was headquartered in Wisconsin. The hospitals were the following:

- Children's Minnesota (Minneapolis, Minnesota)
- Gillette Children's Specialty Healthcare (St. Paul, Minnesota)
- Mayo Clinic Children's Center (Rochester, Minnesota)
- Shriners Hospitals for Children (Tampa, Florida)
- University of Minnesota Masonic Children's Center (Minneapolis, Minnesota)
- Children's Hospital of Wisconsin (Milwaukee, Wisconsin)

Descriptions of these hospitals are found in Appendix 1.

The first content analysis (hereafter referred to as Content Analysis A) examined patient stories' narrative elements and media channels (addressing RQ2 and RQ3). The second content analysis (hereafter referred to as Content Analysis B) examined the prominence of stories on the websites' homepages (addressing RQ3). Data for both content analyses were recorded in an Excel spreadsheet, which is available for review.

The methods, results, and discussion for the content analyses shall be addressed in the following order:

- Method for Content Analysis A
- Method for Content Analysis B
- Results from Content Analysis A
- Results from Content Analysis B
- Results from Content Analyses A and B that highlight unique features from each hospital
- Discussion from Content Analyses A and B

### **Method for Content Analysis A**

To assess what narrative elements and media channels were used in children's hospital patient stories, the researcher first needed to identify stories to analyze. This was a challenge, as each website comprised an unknown, yet likely quite large, number of web pages. Some of these pages included stories, while others did not. To address this, the researcher devised a method for identifying stories using website-specific searches through Google. An explanation of this method is found in Appendix 2.

The researcher identified stories using this method on April 14 and 15, 2018, which yielded 242 unique patient stories. Of this total, 87 patient stories were selected. Six of these stories had a lengthy text article and video on the same web page. To account for differences that could exist between the two channels, the stories on these web pages were examined twice: as a text article and as a video. Thus, 93 patient stories were examined as part of Content Analysis A. The exact number of stories from each website are listed below:

- Children's Minnesota: 15 stories
- Gillette Children's Specialty Healthcare: 16 stories



- Mayo Clinic Children’s Center: 18 stories
- Shriners Hospitals for Children: 15 stories
- University of Minnesota Masonic Children’s Center: 14 stories
- Children’s Hospital of Wisconsin: 15 stories

Data were collected on nine days between April 22 and June 2, 2018, and included the following topics for each story:

- Background information, including the story’s web page URL, title and page header, and publication date (if known)
- Media channel(s) used to present the story
- Narrative elements present in the story, including characters (mentioned and quoted), point of view, subject matter, and theme
- A one- to two-paragraph summary of the story, with material taken verbatim from the story cited with quotation marks
- Miscellaneous items, including calls to action and researcher notes

A copy of the coding sheet that was used is found in Appendix 3.

After data collection, each story was assigned a number, starting at 1 and ending at 93. These numbers shall be used in the analysis that follows to refer to specific stories. A list of the stories’ numbers and corresponding URLs is found in Appendix 4, and samples of stories that were analyzed are found in Appendix 5.

### **Method for Content Analysis B**

Content Analysis B assessed how available, or prominent, patient stories were on the homepages of the six children’s hospital websites. The researcher collected data on June 2 and 3,

2018, which consisted of the following:

- Name of the children's hospital
- Hospital web address (i.e., the hospital homepage URL)
- Date on which the data were collected
- Total number of homepage links that went to second-level pages (the search function on the website did not count toward the total number of links)

In addition, for each hospital, the researcher clicked on all the homepage links and recorded the following information:

- Number of homepage links that went directly to (a) a patient story or (b) a second-level page that contained a list of patient stories (each list containing one or more stories)
- The web addresses and page titles of the links that went to patient stories or lists of patient stories
- For a second-level page that contained a list of patient stories, the number of patient stories in the list

A copy of the coding sheet that was used is found in Appendix 6.

## **Results from Content Analysis A**

The following are results from Content Analysis A, a summary of which is found in Appendix 7.

### **Background information**

Three hospitals (Children's Minnesota, the Mayo Clinic, and the Children's Hospital of Wisconsin) published patient stories in several sections of their websites, a fact indicated by the stories' differing section headers. The Children's Hospital of Wisconsin and the Mayo Clinic had patient stories that were in website sections that corresponded with medical conditions featured

in the stories. For example, Story 81 from the Children's Hospital of Wisconsin focused on an infant with sagittal synostosis (a condition affecting the skull); it was found in the website's craniofacial disorders section. And Story 48 from the Mayo Clinic highlighted a 5-year-old who needed surgery for a heart condition; this story was found in the website's pediatric cardiology section.

Stories from Gillette Children's all had the same section header ("Kids Health Matters"), indicating that they all could be accessed from the same section of the website. This also was the case for stories from the University of Minnesota (its section header was "News & Stories").

None of the stories from Shriners Hospitals had section headers, although most of them were accessible through the website's "Stories" section, which was titled "Why we're here." As of June 24, 2018, the first 10 stories on the "Why we're here" page highlighted NFL players who participated in an initiative that supported Shriners Hospitals. Stories about the hospitals' patients were found further down the web page.

### **Media channels**

Hospitals used text articles and photographs most often to present their patient stories. Ninety-three percent of the stories (n=86) included text articles, and 79 percent (n=73) included one or more photographs. Nineteen percent (n=18) of the stories included one or more videos, and only Story 21 (1 percent of the total) used a media channel in the "Other" category (animated photos).

The majority of the text articles included one or more photographs or a video, with only six text articles having no accompanying photographs or videos.

## Narrative elements

**Characters.** All stories referenced a child who was ill (i.e., the patient), with a little more than one-third of them (n=35, or 37.6 percent) featuring a quote from the patient.

The individual most frequently quoted in the stories was the patient's mother (n=63, or 67.7 percent of the total). She was referenced, but not quoted, in 19 other stories, or 20.4 percent of the total. The patient's father was quoted considerably less than the patient's mother. Only 18.3 percent of the stories (n=17) included a quote from the patient's father. Thirty-eight percent of the stories (n=35) mentioned, but did not quote, the patient's father, leaving 41 stories that did not reference the patient's father at all.

Medical personnel also were referenced in the stories. Sixty-five stories, or 69.9 percent of the total, mentioned a member of the patient's medical team, and 37 stories, or 39.8 percent of the total, quoted a member of the medical team. These percentages add to more than 100 percent because a story could both mention and include a quote from medical personnel if different individuals were referenced and quoted.

Other family members of the patient were referenced in nearly half of the stories (n=41, or 44.1 percent of the total), although they were quoted in only two of the stories (2.2 percent of the total). Finally, other individuals (i.e., characters who did not fit into one of the five other categories) were referenced, but not quoted, in 26 stories (28.0 percent) and quoted in 12 of them (12.9 percent).

**Point of view.** Three-quarters of the stories (n=70, or 75.3 percent) used the third-person perspective. Twelve of the stories, or 12.9 percent, used the first-person perspective, and 11 stories, or 11.8 percent, used both the first- and third-person perspectives. This first- and third-person combination was seen most often in videos, in which the characters' descriptions of their

experiences (first-person accounts) were supplemented with text or voice narration (a third-person account).

**Subject matter.** The stories addressed three areas of the Cancer Control Continuum most frequently: diagnosis (n=72, or 77.4 percent of the stories), treatment (n=83, or 89.2 percent), and survivorship (n=68, or 73.1 percent). Only Story 75 from the University of Minnesota addressed prevention, and 42 stories, or 45.2 percent of the total, addressed detection.

**Theme.** Eighty-eight of the 93 stories, or 94.6 percent, could be categorized into one of the five thematic archetypes proposed by Hawkins (1993, p. 27). Five of the stories (Stories 7, 32, 60, 82, and 89) did not display one of these themes, either because the story was too short, it focused on the patient's regular checkups at the hospital, or it focused more on a secondary character than on the ill child.

The theme that appeared most frequently in the stories was *illness as a battle*; nearly 40 percent of the stories (n=37) had this as their central theme. After this, the *athletic ideal* and *journey into a distant country* themes were most frequent. Twenty-two stories, or 23.7 percent, displayed the athlete theme, and 17 stories, or 18.3 percent, displayed the journey theme. Finally, the *regeneration* theme was central to 8.6 percent of the stories (n=8), and the *healthy-mindedness* theme was central to 4.3 percent of them (n=4).

The researcher found categorizing the stories into one of Hawkins' five thematic archetypes to be the most challenging part of the content analysis. Some of the stories aligned clearly with one theme, while others did so less strongly. Furthermore, some stories contained elements of several thematic archetypes, a reality acknowledged by Hawkins herself in the autobiographies she studied (1993, p. 28). This also may have been difficult because Hawkins observed these themes in autobiographies, or *pathographies*, which are longer than the stories

examined for this research project. The *pathographies* likely provided more opportunities for an author to develop a theme, whereas in the patient stories, the author only had a few hundred words or minutes to accomplish the same task. Still, the researcher did his best to assign one thematic archetype to each story.

**Story summary.** Using data from the story summaries, the researcher identified ways that children's hospitals described their patients and themselves (i.e., the hospitals). Because the researcher did not measure the presence or absence of these descriptions across all the stories during data collection, he cannot assert that one type of description occurs more frequently than another, nor that one hospital uses a particular description more frequently than another hospital.

The following are ways that children were portrayed, with samples from several stories provided (material taken verbatim from the story is in quotation marks).

1. *A normal kid.* The child was portrayed as playful, active, or a "normal kid" like everyone else.
  - Vito is described by his mother as "sassy," "very toddler," and as one who "laughs and giggles" (Story 4 from Children's Minnesota).
  - Gus, 12, who has stage IV Hodgkin lymphoma, gets to "be a 'normal' kid again" by playing soccer with his friends. His mother states, "For Gus, soccer means being with your friends, playing again and having the support of your team" (Story 69 from the University of Minnesota).
2. *Brave or courageous.*
  - Tovin's mother says her 4-year-old son "has been extremely brave and courageous throughout his life's journey" and that he "has taught our family about being strong, both mentally and physically" (Story 6 from Children's Minnesota).

- At age 13, competitive swimmer Alyssia chooses to have her left leg amputated: “She said that prayers and a desire to have an active life were behind her courageous choice” (Story 59 from Shriners Hospitals).

3. *Intelligent and confident.*

- Avital, a teenager, is a budding entrepreneur whose experience wearing a back brace inspired her to consider creating a clothing line for children who undergo similar treatment (Story 16 from Gillette Children’s).
- Katelyn, 4, is described as possessing “an independent, precocious spirit” (Story 26 from Gillette Children’s).
- Despite being born without her left arm, teenager Madelyn swims and plays water polo, and she’s collaborated with Shriners Hospitals to create an anti-bullying toolkit. “She teaches kids that being different is a gift, not a reason to be ridiculed or harassed” (Story 61 from Shriners Hospitals).

4. *Healthy.*

- Kara, 9, was successfully treated for a cleft lip and palate. “Today she is a happy, healthy nine-year-old” (Story 54 from Shriners Hospitals).
- “Today, Gia’s heart is functioning well, she is growing taller and stronger and she has nonstop energy” (Story 67 from the University of Minnesota).

5. *Weak and in need of help.*

- Kathleen, a teenager who has anorexia nervosa and POTS, lacks hope until she meets her medical team. “For the first time in a long time, I felt hopeful,” she stated (Story 9 from Children’s Minnesota).

- As he faces a rare form of brain cancer, 15-year-old Connor states, “I just really couldn’t grasp my mind around it. ... It’s [treatment has] been pretty tough, but [I’ve] gotten through it” (Story 38 from the Mayo Clinic).

The following are ways that the hospitals and their staff were portrayed in the stories (samples are provided, and material taken verbatim from a story is in quotation marks).

1. *An expert who will successfully address the child’s illness.*

- A medical doctor states that “the biggest point of this particular case [repairing a baby’s diaphragm] is the fact that we [the medical personnel] work so well as a multidisciplinary team,” a team that “collaborated” and produced “a great outcome” for the patient (Story 46 from the Mayo Clinic).
- The doctor of 4-year-old Taytem notes that “we [the medical team] were able to halt many of the effects [of her disease, Hurler syndrome] and even turn some back. We were able to stop the ongoing neurologic brain damage and give her a better chance at healthy brain development” (Story 76 from the University of Minnesota).

2. *A compassionate member of the child’s family.*

- Jacqueline, 16, states that she “developed incredible friendships and had such a high level of trust with my care team during treatment [for cancer]. They became like a second family” (Story 12 from Children’s Minnesota).
- Dylan, born 10 weeks early, has exceptional nurses whom his mother describes as “angel[s] by our side.” She continues: “They would tell us what he was doing with love in their voice. It’s a gift they have, not just a job” (Story 80 from the Children’s Hospital of Wisconsin).

3. *A coach who encourages the child to do her best when facing an illness’ obstacles.*



- Avital, a teenager, notes that her medical team “made me feel like my opinion mattered”; she wasn’t a subject who passively received treatments (Story 16 from Gillette Children’s).
- Madelyn, a teenager who was born without her left arm, is inspired to speak to youth about being different thanks to Shriners Hospitals. “They [the hospital staff] instilled courage and confidence in Madelyn and helped her realize anything was possible, even with one arm” (Story 61 from Shriners Hospitals).

*Miscellaneous notes.* The researcher’s miscellaneous notes revealed that, overall, the quality of the stories (from a literary or cinematographic perspective) was good. Exceptional, well-composed patient stories were seen across all six hospitals, as were stories that could be improved. The latter shall be further examined in the hospital-specific results below.

## **Results from Content Analysis B**

The following are results from Content Analysis B. The number of homepage links to second-level pages varied among the hospitals. Shriners Hospitals had the least number of links (N=60), while Gillette Children’s had the most (N=175). The average number of links per homepage was 108.

Gillette Children’s had the largest percentage of homepage links that went directly to a patient story or to a second-level page that contained a list of patient stories. In contrast, the homepage of the Mayo Clinic had the smallest percentage. The percentages for each hospital’s homepage are listed below:

- Gillette Children’s Specialty Healthcare: 13.7 percent (24 of 175 links)
- Children’s Hospital of Wisconsin: 10.0 percent (14 of 140 links)
- Shriners Hospitals for Children: 10.0 percent (6 of 60 links)

- University of Minnesota Masonic Children’s Center: 9.3 percent (8 of 86 links)
- Children’s Minnesota: 8.0 percent (6 of 75 links)
- Mayo Clinic Children’s Center: 6.3 percent (7 of 112 links)

In addition, the researcher measured how many of the website homepage links went directly to a patient story. The University of Minnesota had the most, with 4.7 percent of its homepage links (4 of the 86 links) going directly to a patient story. Three hospitals (Children’s Minnesota, Gillette Children’s, and Shriners Hospitals) had percentages that ranged between 1.1 and 1.7 percent, and the remaining two hospitals (the Mayo Clinic and the Children’s Hospital of Wisconsin) had no homepage links that went directly to a patient story.

Finally, three hospitals (Children’s Minnesota, Gillette Children’s, and the Children’s Hospital of Wisconsin) published stories on pages that were dedicated to diseases or specialties mentioned in the stories. Gillette Children’s, for example, included an appropriate story link on its cerebral palsy page, as did Children’s Minnesota on its cardiovascular program page.

### **Results from Content Analyses A and B that highlight unique features from each hospital**

Data from the two content analyses revealed commonalities among and differences between the hospitals’ patient stories. The following results highlight unique features in the hospitals’ stories and their placement on the websites.

***Children’s Minnesota.*** Of the six hospitals, Children’s Minnesota published the most stories (n=7) that were narrated using the first-person perspective. Four of these seven stories were presented through video, and three of these stories through text articles and photographs.

Several of these first-person accounts convey individuals’ emotions quite strongly. In Story 14, for example, Nikki’s description of what she felt when she learned her newborn

daughter was deaf in one ear is vivid: “Talk about a void in the pit of your stomach; I couldn't breathe. The room began to spin, and I got tunnel vision. I started crying, like sobbing crying. I couldn't believe she was deaf in one ear.” And in Story 9, teenager Kathleen describes what she felt when the Children’s Minnesota staff told her with confidence they could help her face anorexia nervosa and POTS: “From that moment on, everything changed for me. For the first time in a long time, I felt hopeful. The environment at Children’s made me feel different, inspired.”

The quality of one of its first-person stories, however, could be improved. Story 3 is a reprint of a letter parents Jason and Beth sent to the hospital. In it, they thank Children’s Minnesota for the care it provided to their infant daughter. The story, however, does not mention why their daughter had to go to the hospital, nor does it elaborate on setbacks she faced during treatment. This lack of details is understandable considering the message’s original purpose, but it introduces a challenge when shared in a different context. The story may not captivate the public because it lacks details a reader would expect (i.e., the specific challenge the protagonist faced, which in this case is the illness the patient endured).

***Gillette Children’s Specialty Healthcare.*** The majority of Gillette Children’s patient stories (11 of 16 stories) use the *athletic ideal* theme to describe patients’ illness experiences. Story 20, for example, notes that 9-year-old Ava never complains about the many surgeries she undergoes. Instead, according to her mother, Ava “handles everything with bravery and happiness.” And Story 21 introduces the reader to a young woman who receives an electric wheelchair that enables her to stand in place. She appreciates this because it allows her to stand and cheer at University of Minnesota women’s volleyball games. “It’s a chance for all of us,” the story notes, “to be reminded that life’s greatest victories can happen off the court.”

The hospital's stories describe patients as brave, confident, and intelligent. And several of them emphasize that the patients are normal kids, and not simply because they like to play and laugh. Gillette Children's notes that its patients—most of whom have disabilities that cannot be definitively cured—are just like other children who do not have disabilities. Story 27 captures this thought when describing how the parents of identical twins treat them:

The girls' [twins'] parents emphasize to Kiara and Keisy that nothing is “wrong” with them. They do chores, go to school, and have the same responsibilities as their older siblings. “The key is to treat them as equals,” says Vasquez [the girls' mother], “and they will see themselves as equals. Of course we help them more. But we don't treat them differently” (Story 27).

Finally, four Gillette Children's stories only highlight the survivorship area of the Cancer Control Continuum. Two are an article–video combination (Stories 17 and 18) that documents how a 5-year-old girl born without her arms learns to ride a bike, and the other two are an article–video combination (Stories 21 and 22) that documents how a young woman with cerebral palsy is enabled to stand and cheer at volleyball games through a special wheelchair. Only one other story focuses solely on the survivorship area, which was produced by Shriners Hospitals.

***Mayo Clinic Children's Center.*** The majority of stories from the Mayo Clinic (14 of 18 stories) use the *illness as a battle* theme. In addition, several of these stories portray the medical staff as experts who will successfully address a child's illness. Story 34, for example, highlights how staff successfully separated twin girls who were attached at birth. And in Story 43, one doctor comments: ““I think she's got a surgical cure. ... We [the medical team] just took it [a brain tumor] all out, and I don't think there is anything more to do.”” In addition, 13 stories, or 72.2 percent of the total, include a quote from a medical staff person. Only the University of

Minnesota has a larger percentage of stories (78.6 percent) that include a quote from medical staff.

While the researcher did not set out to measure the persuasiveness of text articles versus videos, one article–video combination provides anecdotal support for the media richness theory. Stories 40 and 41 from the Mayo Clinic chronicle the hospital experience of Julia, a teenager who undergoes chemotherapy for leukemia and, as a result of this treatment, has her hips replaced. The text article (Story 40) is a transcript of the narration and interviews in the video version of the story (Story 41). Because of this, one can compare a text article against a video and speculate how these different media channels affect the story.

The researcher found the patient to be more engaging and positive in the video than in the text article, even though both media channels used the same words to present the story. The patient’s tone of voice and facial expressions added a positive affect to her statements, which, in the researcher’s mind, were somewhat pessimistic when read in the text article. (Stories 38 and 39 are another article–video combination from the Mayo Clinic in which the text article is a transcript of the video content. This sample, however, did not draw as strong differences between the media channels as did Stories 40 and 41.)

Six of the Mayo Clinic’s stories include calls to action, the second largest amount among the hospitals. Five of these calls to action ask readers to share the story with others through email or social media.

Some of these calls to action and other story passages are written in a less formal tone. For example, Story 36 invites readers to “Shake your groove thing as you leave a comment below” (the story highlighted a heart transplant patient who danced with her doctors at her wedding reception). And when Story 33 describes how hospital staff don tutus to cheer up a

patient, it notes that one of them “just so happened to have ‘a bag of donated tutus’ handy. (We should all be so lucky.)” Depending on whom the hospital is trying to reach through these stories, this less formal tone may or may not be effective.

*Shriners Hospitals for Children.* Several stories from Shriners Hospitals have extraordinary, larger-than-life characteristics. Story 52, for example, highlights the treatment a teenager from Nigeria received after surviving a plane crash. Story 55 focuses on 15-year-old Jalen, a competitive golfer who participates in the PGA Junior League, and Story 59 highlights a young girl who, despite not having her left leg, swims competitively and hopes to qualify for the 2020 Olympics. It is certainly the case that stories from the other hospitals feature children facing out-of-the-ordinary illnesses. Most of these children, however, come from relatively normal backgrounds that don’t include being a New York City fashion designer (Story 56 from Shriners Hospitals) or acting in television and movies (Story 63 from Shriners Hospitals).

In addition, six stories featured international patients, including children originally from Nigeria, Mexico, Benin, Ukraine, China, and Ecuador.

None of the stories used video. And only 13 individuals were quoted in 11 stories, meaning four stories included no quotes from characters. Only Gillette Children’s and Children’s Minnesota also had stories (two stories and one story, respectively) that did not include a quote from any character.

Finally, Shriners Hospitals did not appear to draw attention to these stories on its website, as other stories about NFL players appeared higher up the “Why we’re here” page than the patient stories.

*University of Minnesota Masonic Children’s Center.* The University of Minnesota references or includes a quote from medical personnel on 21 occasions, a tie with the Mayo

Clinic for the most among the six hospitals. Eleven of these stories include a quote from medical personnel, the second largest amount among the six hospitals.

The hospital's stories display several themes, including the *illness as a battle* theme (n=5) and the *journey into a distant country* theme (n=4).

Nearly all of the University of Minnesota stories (13 of the 15) contain one or more calls to action, most of which invite the reader to learn more about a specific part of the hospital. Story 68, for example, invites readers to "Learn more about University of Minnesota Health Pediatric Diabetes Care and Services," and Story 74 notes that readers should "Learn more about our pediatric infectious disease expertise."

Of the six hospitals, the University of Minnesota has the largest percentage (4.7 percent) of homepage links that go directly to a patient story. Links to these stories were about halfway down the homepage and were displayed as photos of the patients with their names.

***Children's Hospital of Wisconsin.*** None of this hospital's stories displayed the *athlete* theme (the only hospital with this distinction), although it had the most stories that displayed the *journey* theme (n=5). In addition, patients' mothers were quoted in 14 of the 15 stories, the largest quantity and percentage of stories among the six hospitals.

While 10.0 percent of this hospital's homepage links went to a second-level page that contained a list of patient stories, none of these links went directly to a patient story. Yet it was one of three hospitals whose patient stories appeared to be connected with illness-appropriate sections of the website. For example, three of the stories were found in the website's Fetal Concerns Center section, and another two were found in the Herma Heart Institute section.

## Discussion from Content Analyses A and B

The two content analyses provide several findings on how children's hospitals are currently using patient stories on their websites.

*Children's hospitals are using similar narrative elements in their patient stories. But some hospitals appear to be aligning their stories' narrative elements with their public image, or brand.*

Data from Content Analysis A revealed that the six children's hospitals are employing similar subject matters, themes, and portrayals of children and hospitals in their patient stories. The stories commonly focused on the diagnosis, treatment, and survivorship areas of the Cancer Control Continuum. Themes that were observed most frequently in the stories—illness as a battle (39.8 percent of the stories), athletic ideal (23.7 percent), and journey into a distant country (18.3 percent)—are “ubiquitous in pathography” (Hawkins, 1993, p. 61). Hawkins also notes: “Indeed, the pervasiveness of these metaphors suggests that they have become an inherent part of our way of experiencing ourselves and the world” (Hawkins, 1993, p. 61). And data from the story summaries revealed common ways children and hospitals were portrayed. Children were described as normal kids, brave or courageous, intelligent and confident, healthy, and weak. Hospitals and their personnel were described as medical experts, compassionate members of the child's family, and coaches.

While the data show that commonalities exist across all six hospitals, they also suggest that some hospitals are aligning their stories' narrative elements with their public image, or brand. Wheelen, Hunger, Hoffman, and Bamford (2015) define a brand as “a name given to a company's product which embodies all of the characteristics of that item in the mind of the



consumer” (p. 142). “Over time,” they continue, “and with effective advertising and execution, a brand connotes various characteristics in the consumers’ minds” (Wheelen et al., 2015, p. 142).

Many service organizations, such as children’s hospitals, do not have a brand that is associated with a physical product that is purchased and used by consumers. Rather, the organization itself and the services it provides inform the brand. These organizations “build strong brands through distinctiveness, performance, message consistency and by appealing to consumers emotionally” (Kemp, Jilapalli, & Becerra, 2014, p. 127). Some of the children’s hospitals appear to be building their brand by aligning their patient stories with their organizations’ distinctiveness and performance, areas that are highlighted in the hospital descriptions in Appendix 1.

Take the Mayo Clinic. As noted in Appendix 1, it is one of the premier hospitals in the United States and the world. No wonder, then, that its patient stories appear to reinforce its image as a top-notch hospital that successfully addresses illness. For example, the majority of its stories use the *battle* theme, which portrays medical personnel as experts who will defeat illness. Medical staff’s important role is reinforced by being quoting in nearly three-quarters of the stories.

Another hospital whose patient stories support this finding is Gillette Children’s. The hospital serves children who have neurological and musculoskeletal conditions that cannot be completely “fixed” by medical personnel. And most of its patients have disabilities that visibly distinguish them from other children (e.g., they use a wheelchair). The hospital, then, appears to be publishing patient stories whose narrative elements support its overall mission and brand.

For example, the majority of its patient stories do not use the *battle* theme, but instead use the *athlete* theme, which emphasizes that illness is a challenge to be faced with courage,

determination, and humility (Hawkins, 1993, p. 76). Its patients are portrayed as “normal kids” who are just like other children who do not have disabilities. And it is one of two hospitals to publish stories that focus only on the survivorship area of the Cancer Control Continuum. These three features align with the hospital’s image of serving children whose determination helps them thrive with their chronic illness every day of the year.

Shriners Hospitals also appears to publish patient stories that align with the image it wishes to convey to the public. As Appendix 1 notes, the Shriners health care system has 22 hospitals in three countries that serve children with special medical conditions. While it does not use the *athlete* theme as consistently as does Gillette Children’s (even though both hospitals serve children with similar illnesses), it does highlight its international presence by publishing stories about patients from countries outside the United States. Furthermore, it could be attempting to garner attention by publishing stories about its patients who face extraordinary situations.

The researcher sought to determine whether these findings were supported by data gathered from interviews with communication officials from children’s hospitals.

***Children’s hospitals feature patients’ mothers more often in stories than patients’ fathers. The content analysis, however, does not reveal why this is the case, nor if this is something that should be addressed by communicators.***

Across all six hospitals, patients’ mothers were featured more often than patients’ fathers. This is not necessarily a detriment to the stories, but it does raise the question as to why this is the case. It could be that patients’ mothers are more willing or more available to be interviewed for a story. Or it could be that the hospitals want to reach patients’ mothers, so they feature them

in stories more frequently than patients' fathers. Interviews with communication officials at children's hospitals provided data as to why this is the case.

***Children's hospitals present most of their patient stories as text articles with photographs, and most of the stories employ the third-person perspective.***

The media channel used most often to present patient stories was a text article, which was often accompanied by one or more photographs. In addition, most of the patient stories were narrated using the third-person perspective. Through interviews, the researcher discovered whether communications officials at children's hospitals expected these trends to continue, as well as if they were experimenting with other media channels and narration techniques. The researcher was especially interested in their perspectives on media channels given the differences he observed between Stories 40 and 41 from the Mayo Clinic.

***Calls to action focus on providing more medical information to visitors and inviting them to share a story with others. However, the majority of stories do not include calls to action.***

Less than one-third of the patient stories included a call to action. The calls to action that were included focused on providing more medical information to visitors and inviting them to share the story with others. The first call to action suggests that hospitals want to provide helpful information to their prospective patients, while the second call to action suggests they want to spread their name and message to as many people as possible.

***Most children's hospitals publish patient stories in a central location on their website, with at least half of them publishing stories in disease- or specialty-specific sections.***

Data from Content Analysis A revealed that most children's hospitals have a central location on their website where they publish patient stories. This repository is not the website's

homepage, although the latter links to it. At least one of the hospitals (Shriners Hospitals) did not make its patient stories prominent on this repository page, as links to the stories were below nearly a dozen of them that focused on NFL players who supported Shriners Hospitals.

Content Analysis B revealed that at least half of the hospitals publish stories on disease- or specialty-specific sections of their websites, and that most, but not all, of the websites contain homepage links that go directly to a patient story. These facts suggest that while the homepage is an important part of a website, it may not be the most critical location for hospitals to post direct links to patient stories.

## **Interviews**

### **Introduction**

The two content analyses provided several findings on how children's hospitals are using patient stories on their websites. But these findings were merely descriptive, that is, they described characteristics one could observe about published stories. The analyses were not able to elaborate on why hospital communicators might be using particular narrative elements, nor about why they might be presenting these stories through a particular media channel or on a particular section of their website. In addition, the content analyses could not identify whom the hospitals wanted to reach through their patient stories.

In order to address these topics, the researcher conducted qualitative interviews with communicators at children's hospitals. Five officials from four hospitals with locations in the Midwest were interviewed. More information about the interview subjects is provided in the results section below.

### **Method for Interviews**

The interviews were conducted on four days between June 21 and 29, 2018. The interviews lasted between 15 and 35 minutes and were conducted over the telephone. The researcher took notes and did not audio record the conversations. Copies of these notes (which are not verbatim transcripts and have been stripped of information that would identify the subjects) are available for review. Each interview subject has been assigned a number (e.g., interview subject one, interview subject two); this numbering system is used in the results and discussion sections below.

The researcher asked the following questions:

1. What is your position with *[name of children's hospital]* and how long have you been with the hospital? What is your role in publishing and/or creating patient stories for *[name of children's hospital]*?
2. Tell me about your reasons for publishing patient stories on your hospital's website. Whom are you trying to reach through these stories?
3. In what ways do the patient stories you publish match your organization's brand?
4. How do you select children to feature in a patient story? Put another way: Who makes the cut and who doesn't?
5. Tell me about the qualities or characteristics of the children you try to highlight when creating a patient story. Do the qualities you highlight vary depending on the type of story you're creating?
6. What factors lead you to reject a story idea, even though you think it's a good one? Does that include a mismatch between the story and the hospital?
7. Having looked at about 90 patient stories from six children's hospitals, I noticed that children's mothers were featured more often in the stories than their fathers. Thoughts on why this might be? Are there scenarios where you would want to feature one parent over the other?
8. What core messages do you try to convey through the patient stories you publish? Put another way: Is there a "moral of the story" that you try to convey in each story you publish?
9. I notice that some patient stories are written like a news article (from a third-person perspective) and some are written like an autobiography (from a first-person perspective).

Which type do you think is most effective for your hospital to use, and why? What do you see as the difference between the two?

10. How do you decide where to post patient stories on your website (e.g., home page, news page, other pages)? Why this/these page(s)?
11. Looking ahead, do you think video will or should play a greater role in your efforts? If it hasn't, why?
12. Is there anything else about the purpose or value of patient stories that you think is important that I haven't asked?

Originally, the researcher had developed two sets of questions: one for officials who oversaw the creation of patient stories (the managers) and another for officials who created patient stories, such as writers and video producers (the creators). Nine of the questions overlapped between the two sets, and three of them (questions 3, 5, and 9) were specific to the set for creators. The researcher was planning on interviewing an equal number of persons in each group.

But after interviewing his first two subjects (both of whom were managers), the researcher realized that managers likely would be able to answer the questions he had reserved for creators. In addition, he was not able to find equal numbers of managers and creators to interview, and many of the managers he interviewed continued to create patient stories as part of their job duties or had done so in the past. Thus, for the remaining interviews, he asked the subjects all of the questions from both sets. This means that questions 3, 5, and 9 include responses from three of the five interview subjects, and the rest of the questions include responses from all five interview subjects.

## Results from interviews

The following are results from the interviews with communications officials from children's hospitals.

- 1. What is your position with *[name of children's hospital]* and how long have you been with the hospital? What is your role in publishing and/or creating patient stories for *[name of children's hospital]*?**

All of the interview subjects were involved to some degree with developing and implementing a strategy for publishing patient stories on their hospital website. Their work titles included communications specialist, public relations consultant, manager of communications and advertising, senior content specialist, and senior marketing manager.

Interview subjects one and three were involved in media relations and interacting with the community, and interview subjects two and four were charged with managing the creation and publication of patient stories for the hospital. The primary responsibility of interview subject five was to create patient stories by writing text articles and producing videos. Of the four managers, one created some patient stories as part of her current job and two others had done so in previous positions.

The length of time each interview subject had been with his or her hospital varied, from nearly three years to 20 years. Three of the interview subjects' hospitals served children facing a variety of conditions, while one hospital (that of interview subjects two and five) provided specialty services to children.



## **2. Tell me about your reasons for publishing patient stories on your hospital's website.**

### **Whom are you trying to reach through these stories?**

All interview subjects said the primary audience they were trying to reach through patient stories was prospective patients, and more specifically, the parents or guardians of prospective patients. As interview subject four noted, a 3-year-old does not choose which hospital he or she uses. Rather, his or her parents do.

The next most-frequently-cited audience was referring providers. Four interview subjects referenced this group, which consists of pediatricians and other medical professionals who need to refer a patient to another hospital for specialized services. Other audiences cited by the interview subjects were donors (n=3), the community (n=2), prospective doctor employees (n=1), and current patients (n=1).

The overarching reason cited by the interview subjects as to why their hospitals published patient stories was to help their target audiences. But the way a story provided help varied depending on the group of persons it was trying to reach.

Take prospective patients. Members of this audience are adjusting to a new, challenging diagnosis for their child. The purpose, then, of patient stories is to support them as they begin this journey with their child.

How do patient stories provide support? Interview subject one noted that stories can do this by introducing prospective patients to families who had been through similar situations. Interview subject four focused not on how stories introduce prospective patients to other families, but on how they introduce them to the hospital's doctors. Stories, she said, can help humanize these doctors and, hopefully, make the situation less scary. Interview subject five

noted that these stories should provide credible medical information to parents about their child's condition, which will hopefully persuade them to choose the hospital.

Another audience interview subjects discussed was referring providers. Stories help these providers by showcasing the medical expertise of the hospital. Interview subject three noted this gives the providers peace of mind that the hospital is a good choice. And interview subject four said that her hospital's stories attempt to include quotes from the provider who was involved with the case.

### **3. In what ways do the patient stories you publish match your organization's brand?**

Two of the interview subjects said that they seek to align patient stories with the hospital's overall brand strategy. Interview subject five, for example, noted that her hospital, which treats children with cerebral palsy, publishes stories about children with this condition during Cerebral Palsy Awareness Month in March.

In describing his hospital's brand, interview subject three referenced eight values that his hospital espouses. Two of these values that it attempts to communicate in patient stories are teamwork and compassion. Teamwork refers to the way the medical staff provide integrated care to patients, and compassion refers to how the hospital staff supports, or journeys with, patients and their families throughout their illness.

### **4. How do you select children to feature in a patient story? Put another way: Who makes the cut and who doesn't?**

Several interview subjects indicated that the stories they publish need to align with their department's communications goals. For example, interview subject one said on one occasion, her team sought to feature families who had received care through her hospital's fetal care

program. Growing this new program was a business objective for the hospital, so publishing stories about families who had received care through it could help advance this objective.

Interview subjects also discussed how their departments received ideas for patient stories. Four interview subjects said medical providers supplied them with ideas and (according to interview subject three) only after the provider had asked the patient and his or her family if they would be willing to participate. The interview subjects also received ideas from patients directly. Two interview subjects said that these patients want to share their stories to help other families experiencing similar situations.

Interview subjects three and four identified several factors that influenced whether and how they would publish a patient's story. Interview subject three said his team asks questions like, "Is the story easy to understand?" "Is it visual?" and, "Is it timely?" Interview subject four said all of her hospital's stories have to have a visual element, typically a photograph. Because of this, the patient needs to live relatively close to the hospital so a member of her team can interview them in person and take a photo. Finally, before her team tells a patient story through video, it first determines whether the patient and his or her family is comfortable on camera. If they're too nervous and cannot tell their story well on camera, then her team will not use that media channel.

**5. Tell me about the qualities or characteristics of the children you try to highlight when creating a patient story. Do the qualities you highlight vary depending on the type of story you're creating?**

Interview subject four said the characteristics her hospital highlights depend on the objective of the story. This was echoed by interview subject five, who noted that her hospital tries to feature a diversity of children with different conditions.

Still, the interview subjects did note characteristics they try to highlight in every story they publish. Interview subject four said her hospital seeks to convey the child's personality. Not only does this respect the child (after all, she is sharing her story during a difficult time), but it also makes the story more authentic. If all her hospital's patient stories relied on marketing language and stock photos, she continued, they wouldn't sound authentic nor be as effective.

Interview subject three said his hospital wants to make sure that every child it features is experiencing healing and hope in some way. Healing, he emphasized, is not necessarily a cure.

#### **6. What factors lead you to reject a story idea, even though you think it's a good one?**

##### **Does that include a mismatch between the story and the hospital?**

Four of the interview subjects noted they will reject an idea if it isn't the right time for the patient to share his or her story. Interview subject two, for example, noted there may be family dynamics that make it inopportune to publish the story, and interview subject one noted the patient may not be emotionally ready to share what he or she has experienced. Interview subject three noted that if the patient feels pressured to share her story (in order, for example, to please her physician), his hospital will not pursue it. And, as interview subjects one and four noted, if the patient's prognosis is not good, their hospitals will not pursue the story. All of these scenarios would lead the hospitals not to publish a patient story.

Two interview subjects stated they have rejected story ideas when they do not align with their team's and the hospital's overall goals. Interview subject four said her team has rejected stories when items mentioned in the stories are changing at the hospital. For example, a medical provider who cared for a patient might be leaving the hospital, or a service that was offered to a patient is changing. And interview subject five said there have been scenarios where she or a member of the communications team has interviewed a child who is nice, but whose story isn't

compelling and doesn't align with the hospital's overall goals. In these rare cases, she continued, the hospital hasn't used the story.

Finally, interview subject one noted that her hospital uses most of the story ideas it receives—those that come from providers and those that come from patients directly—although when and how it publishes them varies. If the idea features a new or innovative treatment, her team might pitch it to media outlets and not produce a story in-house. Or if the idea features a child experiencing a common medical condition, her team might publish a photo with a cutline and not produce a text article or video. She said her team doesn't have a one-size-fits-all vision for storytelling; rather, it uses different approaches that work best for specific stories.

**7. Having looked at about 90 patient stories from six children's hospitals, I noticed that children's mothers were featured more often in the stories than their fathers. Thoughts on why this might be? Are there scenarios where you would want to feature one parent over the other?**

The interview subjects indicated they do not intentionally try to feature the child's mother more than the child's father in the stories they publish. In fact, they said they attempt to feature both whenever possible. Interview subject three noted the only case where he'd want to speak to a particular parent is if he or she is the primary caregiver for the child and capturing that parent's perspective is necessary for the story. Still, he said he's never made the case that his hospital's stories should only focus on the child's mother and not on the child's father.

Two interview subjects noted that family logistics likely play a role in this disparity. Oftentimes, the child's mother is at the hospital more than the child's father and, therefore, is more available to be interviewed. The father, meanwhile, may be taking care of other things for the family, interview subject four noted.

Still, two interview subjects noted that data show that mothers typically are the health care decision makers for their families. So if children's hospitals want to reach prospective patients, featuring mothers in patient stories may not be a poor decision.

**8. What core messages do you try to convey through the patient stories you publish? Put another way: Is there a “moral of the story” that you try to convey in each story you publish?**

Interview subject one stated the core message her hospital tries to convey is hope, in particular to those patients and families who are beginning their illness journey. She said her team wants these stories to provide comfort to families.

Two interview subjects noted they want the stories to showcase their hospital's expertise. Interview subject five said her hospital wants prospective patients to know that it offers a wide range of services, all of which are used to craft individualized care plans for patients. Similarly, interview subject four said her hospital wants patients to know that it handles a variety of medical conditions.

Finally, two interview subjects (both of which worked for the same hospital, which provides specialized services to children) said a core message their hospital communicates is that their patients can do many things. Interview subject two said her hospital's stories try to focus on what patients can do—not what they can't do—and how the hospital helped them achieve that. And interview subject five said her hospital wants its patients to be seen as active and out in the community.

**9. I notice that some patient stories are written like a news article (from a third-person perspective) and some are written like an autobiography (from a first-person**

**perspective). Which type do you think is most effective for your hospital to use, and why? What do you see as the difference between the two?**

The three interview subjects did not have data that showed in what scenarios a first-person account might be more effective (however that is measured) than a third-person account, and vice versa. Interview subject three suggested first-person accounts have become more common due to the emergence of online blogs, as well as that first-person accounts could be powerful in reaching potential patients who are looking for recommendations and advice. People like to read about individuals' experiences, he said.

Interview subject four noted it is difficult for children's hospitals to publish stories told from the first-person perspective because their patients are children. In general, these patients aren't able to express themselves well, which is why the hospital's communications team is critical for capturing their stories and expressing them from the third-person perspective. The communications team also can help a parent who wants to share his story as a first-person account, interview subject five noted. Even if the parent writes well, he likely isn't professionally trained, interview subject five said. She and members of her team, then, can coach the parent so he delivers his message in the best possible manner.

**10. How do you decide where to post patient stories on your website (e.g., home page, news page, other pages)? Why this/these page(s)?**

Most interview subjects were not involved in deciding where the patient stories should be posted on their hospital's website. Interview subject one, for example, noted that her hospital has a digital team that uses website traffic and analytics to determine where the stories should be located, including how many to include on the homepage.

Still, several of them noted that their hospital's patient stories reside at a common location on the website. This oftentimes was a blog or newsroom page. These same interview subjects also noted that their stories are tagged so that they appear on pages dedicated to other topics. Interview subject one, for example, noted that if a story was about a child whose appendix burst, it would appear on the website's blog and in its emergency care section, as the latter department would have treated the child.

In addition, interview subjects two and four noted that their teams discuss other online platforms where they can share patient stories. Interview subject four said her hospital might provide a short snippet about a story on Facebook and link that snippet to the complete story on its website. And interview subject two said she meets with her team once a week to discuss which platforms (including the website, Twitter, YouTube, and Instagram) make the most sense for sharing particular stories.

**11. Looking ahead, do you think video will or should play a greater role in your efforts? If it hasn't, why?**

Three of the interview subjects said their hospitals are looking to produce more videos that tell patient stories. But the interview subjects also noted that this choice still needs to connect to hospital's overall communication objectives. For example, interview subject three said selecting a media channel depends on the story's goal. If his hospital wants to convey detailed information in a story, it likely will use a text article, whereas it might use a video if the story is visual. Furthermore, interview subject four noted that some of her hospital's objectives lend themselves to longer videos (i.e., several minutes), while others can be accomplished through short videos that are created on a team member's iPhone and shared on social media.



But as interview subject one noted, even if a story would be told most effectively through a video, this may not occur if the patient and his or her family aren't comfortable on camera. She expects this trend to continue.

Finally, interview subject one noted that her hospital is using video to tell patient stories that cover an extended period of time. For example, her team might work with a family to capture footage as the child is diagnosed with an illness, receives treatment at the hospital, and lives her life after treatment. She said this is a great way to show the long-term impact of the treatment a child receives at the hospital.

**12. Is there anything else about the purpose or value of patient stories that you think is important that I haven't asked?**

Interview subject one said her hospital uses an outside agency to help write some of the patient stories it publishes.

Interview subject two noted that stories are the best way to relate to people, especially since they're being bombarded with a plethora of information from many companies. She said when a hospital can connect with individuals through stories, they're making the best kind of connection.

Interview subject three said from his experience, patients and families are willing to share their stories if they know doing so will help other people. And interview subject four said stories are a great way to show how a hospital is connected to the community at large.

Finally, interview subject five emphasized it is important for parents to hear from other parents who have had the same experiences. Not only do her hospital's stories introduce readers to these parents, but they also provide solid medical information that can help parents along their journeys.

## **Discussion from Interviews**

The five interview subjects provided a wealth of information regarding how their hospitals use patient stories to advance their organizations' objectives. The following are findings from these interviews, which address some of the questions that surfaced from the two content analyses.

***Communications officials seek to align the patient stories they publish with their hospital's brand and overall communications objectives.***

The interview subjects indicated that the patient stories their hospitals publish need to align with their brands and communications objectives. Examples that support this include publishing stories that highlight a new department or program and aligning the story's messaging with the hospital's company values. Interview subject five noted that her team has not pursued patient stories if they haven't aligned with the communication department's overall goals.

The key, then, for communications officials is knowing their hospital's brand and communications objectives. This will affect several things, including the hospital's target audiences and the core messages it seeks to convey.

***Children's hospitals want to reach prospective patients (in particular, a child's parents or guardians) and referring providers. This, in turn, appears to influence the core messages they convey in patient stories.***

All the interview subjects indicated that they want to reach prospective patients through patient stories, and four of them noted they are also targeting referring providers. While the needs of these audiences are different, they are similar in that both groups want educational information and both are looking for peace of mind in some manner. Regarding the latter, the parent asks, "Will this hospital heal my little girl whom I love?" while the physician asks, "Does

this hospital know what it's doing? Do I trust its staff, that they will provide exceptional medical care to my patient?"

It appears, then, that the core messages children's hospitals are trying to convey through patient stories (at least those messages identified by the interview subjects) align with the needs of these audiences. Interview subject three introduces a pair of words that sums up well the core messages identified by the interview subjects: teamwork and compassion.

*Teamwork* captures how children's hospitals are portraying themselves as medical experts to their key audiences. As several interview subjects noted, they want their hospital's medical staff to be viewed as a collaborative team whose depth of knowledge brings healing to patients. By reading these stories, then, parents and guardians will receive credible information about their child's new diagnosis. And referring providers will be convinced that the hospital and its medical staff know what they're doing. This is why interview subject four's hospital seeks to weave in quotes from its medical providers.

The other theme children's hospitals want to convey through stories is summed up by the word *compassion*. Interview subjects indicated that their hospitals want to provide *hope* to parents and guardians who are adjusting to their child's new diagnosis. One way they do this is to publish stories about patients and families who have been in similar situations. Another tactic they employ is showcasing the compassion of their medical staff. Interview subject four noted that her hospital publishes question-and-answer articles with its physicians; these articles help humanize the doctors and show that they're friendly. By portraying themselves as compassionate bearers of hope, hospitals are trying to bring peace of mind to prospective patients who are adjusting to their child's new diagnosis.

*Children's hospitals that provide specialized services may be able to develop and communicate messages that distinguish themselves from other hospitals that provide a broad range of services.*

Interview subjects two and five were the only two who mentioned that they try to convey what children *can* do in the patient stories they publish. They also both worked for a hospital that provided specialized services to children, and they noted that they try to reach donors and the community through their stories. The data suggest that this hospital's messaging, which focuses on what children *can* do, aligns with the types of services the hospital provides. Even when children need to receive specialized care, they still *can* do many things. This unique messaging, then, could provide the hospital with an advantage as compared to other hospitals that provide a broad range of services. Furthermore, the hospital might be using this messaging in order to reach donors and the community at large.

*Communications officials know there are a number of variables that affect how patient stories are crafted and presented, as well as whether the stories will be published at all.*

Data from the interview subjects revealed that oftentimes there are a number of factors outside of the communications officials' control that determine who is featured in a story, who narrates it, and what media channel is used.

All of the interview subjects indicated they were open to—and welcomed—interviewing both the patient's mother and father. But as two interview subjects noted, interviewing both parents can be logistically difficult. The child's mother likely is at the hospital more often than the child's father, making it easier to interview her for a story. This limitation, however, may not hurt hospitals, being as data show mothers typically are the health care decision-makers for their children (Kemp, Jillapalli, & Becerra, 2014, p. 133). Still, if a hospital is starting a new program

that is geared toward fathers, or if it wants to share a story that features a father's perspective, it likely will need to capture their stories.

Like Stern (1991), interview subject three suggests that stories told from the first-person perspective could be better than third-person stories at different tasks, whether it be developing a personal relationship with readers (Stern, 1991, p. 12) or providing them with recommendations and advice. Yet as other interview subjects admitted, it is difficult for children's hospitals to find and publish first-person patient stories. Many of their patients are young, meaning they aren't able to express themselves well in an interview setting or if asked to write. And those patients who are able to express themselves well in an interview (typically teenagers) may not be able to do the same in writing. Thus, if a children's hospital wants to include more first-person patient stories on its website, it will need to find the right patients and, as interview subject five notes, rely on its communications staff to assist them in the writing process.

Another way hospitals could share first-person patient stories is through videos, a medium that several interview subjects indicated their hospitals want to use more frequently. Interviewing patients on camera eliminates needing to have them write down their experiences. Yet interview subject one noted that not all children and their families are comfortable speaking in front of a camera. And while some stories are visual and lend themselves to a video presentation, others are not, in particular stories that need to convey detailed information. Furthermore, creating a video requires more equipment—including cameras, audio recorders, and editing software—than does composing a text article. And for any patient story, the communications staff needs to receive permission from a child's parents or guardians before pursuing it. This is especially the case for a story presented through video.

Finally, the interview subjects emphasized that the right circumstances have to be in place before they publish a patient story. The patient and her family might not be ready emotionally to share their story, or they might feel pressured to do so. A poor prognosis and negative family dynamics also might dissuade the hospitals from publishing the story.

*The homepage is one of several locations where children's hospitals are publishing patient stories. A common repository page and disease-specific pages on a hospital's website, as well as social media channels, are other locations they're using.*

When asked how their team chooses where to publish patient stories on their hospital's website, two interview subjects said stories are published in a central location and are tagged to appear on disease- and specialty-specific pages that relate to the story. And two others noted their teams discuss a variety of platforms where the stories could be published, including the hospital's website and social media channels (e.g., Facebook, Twitter, YouTube, and Instagram).

None of the interview subjects mentioned the website's homepage as a location where patient stories needed to be posted. In fact, interview subject one said her hospital's digital team recently determined that only one patient story should be directly linked to the homepage (not three or four as was the case with the hospital's previous website). Still, the central location where the patient stories are published needs to be findable, which likely means there should a link to this page on the hospital's homepage.

This, coupled with interview subject one's admission that her hospital relies on its digital team to choose where stories should be published, suggests that children's hospitals want their stories to reach their intended audiences. Furthermore, a homepage link that goes directly to a patient story is one among many strategies children's hospitals are using to present their stories to the public.

## Findings

This research project sought to answer the question, “What is the relationship between different children’s hospitals and how they use patient stories on their websites?” To clarify the question, three additional research questions were developed:

- RQ2. How are children’s hospitals crafting patient stories? That is, what narrative elements are they commonly including—if any—in the patient stories they create for their websites?
- RQ3. How are children’s hospitals presenting patient stories on their websites? This includes the placement, or prominence, of the stories on the sites and the media channels used to present the stories.
- RQ4. What individuals do children’s hospitals want to reach through the patient stories they publish on their websites?

To answer these questions, two content analyses of patient stories from children’s hospital websites were conducted and interviews were held with communications officials from four children’s hospitals. The following are findings from this research.

**Children’s hospitals are using patient stories to reach their target audiences. These target audiences influence how the stories are crafted and what narrative elements are featured.**

A principal finding is that children’s hospitals want their patient stories to reach prospective patients and referring providers. All five interview subjects said their hospital’s primary audience for these stories was prospective patients, that is, parents and guardians whose child had recently been diagnosed with an illness. And four of the five subjects said referring providers was another audience they wanted to reach.

This insight that prospective patients are a target audience is supported by data from Content Analysis A. The majority of its stories focused on the diagnosis, treatment, and survivorship areas of the Cancer Control Continuum, with only 45.2 percent focusing on detection and 1.1 percent focusing on prevention. This likely is the case because parents and guardians already know their child has cancer, diabetes, cerebral palsy, or other illness. They are not looking to prevent an illness from occurring in their child, nor do they need information to help determine if their child has an illness. Rather, they likely want information on treatments that are available, the doctors who would perform these treatments, and what they can expect throughout the process—all items that relate to the treatment and survivorship areas. These needs were confirmed by the interview subjects, who noted that they try to include credible medical information in their stories and highlight families whose illness journeys exude hope. And data from Content Analysis A suggests that the University of Minnesota responded to these needs by including calls to action in its stories that provided the reader with more information about the hospital's services and departments.

Another data point from Content Analysis A that supports this finding is the characters who were featured in the stories. Nearly 90 percent of the stories referenced or quoted the child's mother, and 55.9 percent referenced or quoted the child's father. If, as interview subjects one and five noted, patient stories can provide support to parents and guardians by introducing them to others who have been through similar experiences, then referencing these characters in the stories is critical.

Furthermore, several interview subjects noted that data show that women are the primary health care decision-makers for their families. Thus, by featuring children's mothers more than children's fathers, the hospitals could be narrowing their target audience—from the larger target



of parents and guardians to the smaller target of health care decision-makers. (Logistical factors that likely make it easier to capture mothers' perspectives than fathers' perspectives shall be discussed below.)

If prospective patients and referring providers want credible medical information and hope, are the messages in patient stories delivering this? The data appear to indicate the answer is yes. Two messages that several interview subjects said they seek to convey are *teamwork* and *compassion*. Teamwork focuses on the medical expertise of the hospital and its staff, while compassion showcases how the hospital staff accompanies patients and their families through all the ups and downs of their illness journey. These messages were also seen in data from Content Analysis A. The individuals who created the patient stories frequently described the hospitals and their medical staff as experts who could successfully address a child's illness and as compassionate members of the child's family. These messages were further emphasized by medical providers being mentioned in 68.8 percent of the stories and quoted in nearly 40 percent of them.

**Children's hospitals are using common messages and ways of describing children in their patient stories. The researcher did not discover new thematic archetypes that are unique to these patient stories.**

As mentioned above, the researcher discovered two messages children's hospitals want to convey through patient stories: teamwork and compassion. He also discovered common ways children were described in the stories (e.g., normal, brave or courageous, etc.), and interview subject four emphasized that the child's personality should always shine through, as this makes the story more authentic. Thus, it appears that hospital communicators, at a minimum, should consider these elements as they craft patient stories.

The researcher was open to learning whether the stories used different thematic archetypes than those proposed by Hawkins. He admits it was difficult to assign a theme to some stories, in particular to those that did not clearly display one. Still, he did not identify new themes that were unique to patient stories published by children's hospitals.

**Children's hospitals with well-known brands and those that provide specialized services are using particular narrative elements in the stories they publish, which could help them stand out from their competition.**

Thus far, the researcher has shown how several narrative elements commonly found in patient stories (the focus of RQ2) align with the finding that patient stories' primary audiences are prospective patients and referring providers (the focus of RQ4). But the data also suggest that some children's hospitals are using particular narrative elements to support their public image, or brand.

One example is the Mayo Clinic. It is known throughout the world as a premier medical destination. It makes sense, then, that 77.8 percent of its stories in Content Analysis A used the *illness as a battle* theme, as well as that 13 of these stories included quotes from medical personnel (the largest number among the six hospitals analyzed). The hospital wants to be seen a medical expert that will successfully defeat illness, so it uses narrative elements in its stories that support this.

Another children's hospital that appears to be using narrative elements to support its brand is Gillette Children's. It provides care to children with complex musculoskeletal and neurological conditions, many of which the children will have their entire lives. Thus, it makes sense that 68.8 percent of this hospital's patient stories use the *athletic ideal* theme, which emphasizes that illness is a challenge to be faced with courage, determination, and humility.

These qualities are exuded by many of the hospital's patients on a daily basis as they face cerebral palsy, scoliosis, and other neuromuscular disorders. Furthermore, Gillette Children's was one of two hospitals with stories that focused solely on the survivorship area of the Cancer Control Continuum. This area focuses on how a patient lives, or survives, after being treated for an illness. Given its patient population, it makes sense that Gillette Children's has published stories that simply highlight how its patients are living and thriving.

A final data point that supports this finding comes from the interviews with communications officials. Interview subjects two and five worked at a hospital that provided specialized services to children, and they both mentioned that their hospital tries to convey in its patient stories what children *can* do, not what they can't do.

What, then, do these examples from Content Analysis A and the interviews show? They suggest that hospitals with well-known, distinguished brands (like the Mayo Clinic) and hospitals that provide specialized services (like Gillette Children's and the hospital referenced by interview subjects two and five) are using particular narrative elements in their stories that align with their public images. One can assume that this alignment strengthens the hospital's brand, helping distinguish it from others in the marketplace.

The challenge, then, appears to be for children's hospitals that provide a variety of services but aren't as well-known or as specialized as the ones mentioned above. This research project suggests that in order to succeed, these hospitals, at a minimum, must know whom they want to reach and develop messages that address their needs. Other tactics might include highlighting an area that distinguishes the hospital from others (such as interview subject one's hospital did with its fetal care program) or drawing attention to extraordinary patients and illnesses (like Shriners Hospitals appeared to be doing in its patient stories).

**Children’s hospitals are looking to publish more stories in video format, and they’re open to publishing stories narrated from the first-person perspective. But these variations must align with the hospital’s overall communications goals, and there are practical limitations officials will encounter in pursuing them.**

An element that could help a children’s hospital distinguish its stories from others is media channel. The majority of the patient stories analyzed in Content Analysis A were text articles, with only 19.4 percent of them being presented through video. Yet several interview subjects noted their hospitals want to produce more video-based patient stories. If their goal in doing so is to provide hope to prospective patients by sharing what other families have experienced in difficult situations, then the media richness theory supports this decision. This is also supported by differences the researcher observed between Stories 40 (a text article) and 41 (a video) from the Mayo Clinic. Even though the patient was quoted the same in both stories, she appeared more engaging and positive in the video than in the article.

However, as interview subject three noted, the media channel used for a story needs to align with the hospital’s overall communications goals. If, for example, one needs to convey detailed information in a story, then a text article likely is a better choice than video. And if one chooses to use video for this type of story, one must develop creative, effective ways to convey the information.

Point of view is another narrative element that could help differentiate a hospital’s patient stories and have them make a greater impact with readers. Most of the stories examined in Content Analysis A were told from the third-person perspective, with 12.9 percent being told from the first-person perspective and 11.8 percent from both the first- and third-person perspectives.

The interview subjects did not know in which situations a first-person account would be more effective than a third-person account, although interview subject three thought first-person accounts could be especially adept at conveying experiences of and recommendations from current patients. This echoes Frank's (1994) assessment (although perhaps not as negatively) that the reader "confronts the ill person as an active subject" in a first-person account (p. 3), as well as Stern's (1991) hypothesis that first-person accounts are adept at establishing "a personal relationship between the presenter and an audience" (p. 12). And according to interview subject four, what mattered most in choosing one perspective over the other was which one resonated most with the target audience.

The interview subjects revealed, however, that hospital communicators will face challenges in publishing more stories that use video and the first-person perspective. Some patients and their families have exceptional stories, but if they aren't comfortable in front of a camera, then that media channel is not an option. Furthermore, few young children are able to talk about their illness experience, let alone compose a first-person account of it. And for those children and family members who are able to articulate their experience, they may not be able to write it down. Indeed, as several stories published by Children's Minnesota demonstrate, first-person accounts vary in literary quality. Thus, hospital communicators need to be aware of these limitations and be ready to help patients and their families express themselves on paper or in front of a camera.

**Children’s hospitals are publishing patient stories on their websites in a common repository and on disease-specific web pages. The prominence of stories on the homepage may not be the best measure as to whether they are reaching target audiences.**

Research Question 3 asked how accessible, or prominent, patient stories were on the websites of children’s hospitals. The research shows commonalities among the hospitals.

First, children’s hospitals are publishing patient stories in two primary locations on their websites: in a common repository (oftentimes a website’s blog or newsroom) and on disease- or specialty-specific web pages that relate to the story. Data from Content Analyses A and B showed that hospitals were publishing their stories on disease-specific pages, which was supported by comments from two of the interview subjects.

Furthermore, data showed that most hospital homepages did not contain direct links to patient stories, but instead contained links that went to second-level pages with lists of patient stories. According to Content Analysis B, between 6.3 and 13.7 percent of the six hospital’s homepage links went to a patient story or list of patient stories. Two of the hospitals, however, did not have links on their homepages that went directly to a patient story. For the other four hospitals, two of them had one direct link to a patient story, one had two direct links, and another had four direct links. Interview subject one supported this minimalist strategy, noting that her hospital’s digital team had determined that only one homepage link should go directly to a patient story.

This data suggest that the presence of a homepage link that goes directly to a patient story may not be the best measure of whether the story is reaching visitors. Rather, a hospital’s digital team can use website traffic and analytics to determine where the stories should be located. And

as several interview subjects noted, hospitals should consider other platforms to publish patient stories, including Facebook, Twitter, YouTube, and Instagram.

**Children’s hospitals should publish stories that better address the needs of one of their key audiences: current patients.**

The aforementioned findings demonstrate that different children’s hospitals are using similar techniques in presenting patient stories to their key audiences. These similarities include the narrative elements featured and where the stories are published. So to respond to this project’s central research question: There aren’t many differences amongst the stories published by the children’s hospitals that were examined. Still, the findings do show that some hospitals (the Mayo Clinic, Gillette Children’s, the hospital of interview subjects two and five, and even Shriners Hospitals) are reinforcing their images, or brands, by using particular narrative elements.

But are there ways these children’s hospitals can improve how they use patient stories? The researcher thinks there are.

Data from Content Analysis A and the interviews revealed that, overall, children’s hospitals are choosing to publish stories that present patients, family members, medical staff, and medical outcomes in a positive, hope-filled light. For example, none of the stories had a central theme that focused on death and dying, and when asked what would lead their hospital to reject a patient story, two interview subjects noted a poor prognosis for the patient was a factor. Instead, hospitals want their stories to focus on *teamwork* and *compassion*, messages that naturally align with the battle and athlete themes observed in 63 percent (n=59) of the stories.

The question, though, is whether this is the only way children’s hospitals should present patient stories to their key audiences. If the hospital’s goal is to provide reassurance to

pediatricians, then showcasing the hospital's medical staff and outcomes in a positive light is critical. And if the goal is to provide hope to parents and guardians whose child has recently been diagnosed with an illness, then presenting stories with successful outcomes makes sense.

But what about patients whose prognoses aren't good? One of a hospital's audiences (only identified by one of the interview subjects) is current patients. Many of these individuals have been undergoing treatment for months or even years. They and their parents do not know what the ultimate outcome will be; they're enmeshed in the challenges and stress that accompany surgeries, chemotherapy regimens, extended hospital stays, and more. Patient stories with positive outcomes may have initially been helpful for them, but they likely no longer are useful for patients as their treatments continue with no end in sight.

The question, then, is whether children's hospitals should only publish patient stories that have positive or uplifting outcomes. More fundamentally: Is publishing these types of stories the only way hospitals can provide help and support to patients and their families, a key objective identified by the interview subjects? Can a patient develop an affect-based brand relationship with a children's hospital only by reading stories that are filled with hope (Kemp, Jillapalli, & Becerra, 2014, p. 127)?

The researcher thinks the answer to these questions is no. Children's hospitals should consider publishing patient stories that better address the needs of current patients.

How can communicators at children's hospitals accomplish this? First, they can highlight themes other than *illness as a battle* and the *athletic ideal* in their patient stories. Both of these themes (as seen in the stories analyzed in Content Analysis A) tended to include medical personnel successfully treating an illness or patients facing their conditions with courage and humility. But for many patients, not every treatment plan succeeds, and they aren't always brave



and courageous. The researcher thinks that *death and dying* themes and the *journey into a distant country* theme are better positioned to highlight the ongoing challenges patients endure. In particular, the latter captures any “exploration of the unknown, the dangerous, and the frightening” (Hawkins, 1993, p. 78).

Two examples suggest how patient stories could do this. Story 66 from the University of Minnesota highlighted a photo project in which families of six patients were given a camera and invited to take photos of their child’s hospital experience over nine months. The families took more than 7,000 photos, a selection of which were eventually displayed at a public exhibit. The story introduced the reader to the project and included six photo examples and accompanying quotes from family members. One of these quotes acknowledged that Anton, the child in the picture, had died. “The picture I chose,” wrote Anton’s mother, “is a shot of our family snuggling with Pete the Cat, who is my son Anton’s favorite character in a book. . . . It’s just a very special moment that we got to spend with him before he passed away.”

Story 70 from the University of Minnesota used the *journey into a distant country* theme by showing the transformation Tracy underwent as her daughter, Charlotte, was treated for a severe form of epilepsy. “From the minute she was born, we experienced this loss of joy,” Tracy stated at the beginning of the article. “We didn’t get to share in the same things as other young families.” But by the article’s end, one learns that Tracy is going to run the Twin Cities Marathon to honor Charlotte and the suffering she undergoes. “There’s joy in everything, and we believe that the joy is the root of happiness,” Tracy stated. “For me, the marathon is not only about SCN2A awareness. Running it also represents a small part of the sacrifice and pain that Charlotte has to go through.” Indeed, the article did not sugarcoat Charlotte’s illness. In fact, it noted that Charlotte’s family and doctors were still grappling with how to provide her with

effective treatment: “Since then [her first three months of life, which were spent in the hospital’s NICU], Charlotte has been hospitalized 11 more times for respiratory infections and severe seizures. She is currently on seven seizure medications, though her complications continue.”

Communicators likely will hesitate to publish these types of stories on their hospitals’ websites, as they do not match the typical ways that illness is portrayed in public narratives (Hawkins, 1993, p. 61). Yet doing so will address the needs of one of their key audiences: current patients. These stories will *provide support* to patients and their families, a strategic goal identified by the interview subjects and executed by them in similar ways (i.e., focusing on teamwork and compassion). If, as interview subject four suggested, authenticity in storytelling is important, then publishing stories that do not sugarcoat the challenges patients and their families face (even when this differs from how patients and medical staff are typically portrayed) is critical.

One should publish these stories in the website’s common repository and tag them to appear on other appropriate pages (e.g., a page that highlights the hospital’s spiritual care services). If hospital leadership does not want to do this, communicators could compile these stories and publish them in a print piece, which then could be given to patients and their families on an individual basis. That way, the stories could be shared in a manner that reduces the possibility of them reaching a large audience through the internet.

Another tactic that could result in stories that are better suited for current patients is to share a patient’s illness journey through a series of stories, not just a single story. Communicators could be using the same narrative elements in story after story (e.g., battle and athlete themes, portrayals of children as brave and courageous) because they only have a few hundred words or minutes with which to work. Sharing a child’s illness experience through a

series of articles or videos allows communicators to highlight all the ups and downs a patient experiences. Interview subject one indicated her hospital was using this tactic with some of the videos it published; it should continue to do so, and other children's hospitals should look to adopt this practice.

## **Limitations and Future Research**

To address this project's questions, the researcher conducted two content analyses and held interviews with five communications officials from four children's hospitals. While these methods provided a wealth of data, they also had weaknesses that limit the generalizability of the findings to all children's hospitals.

First, sample sizes for the content analyses were limited. The researcher analyzed stories from six children's hospitals in the Midwest, despite there being more than 200 of these hospitals in the U.S. Thus, the results cannot be generalized across all children's hospitals. In particular, the small sample size affects the finding that hospitals with well-known brands and those that provide specialized services are using particular narrative elements in their stories to reinforce their brands. This was observed only in three hospitals: the Mayo Clinic, Gillette Children's, and the hospital mentioned by interview subjects two and five. Future research with other well-known or specialty-care hospitals might weaken this finding or disprove it altogether.

In addition, the researcher examined 93 patient stories. While this is a large number, it is not a random sample that accurately represents all the patient stories that were on the hospitals' websites. In fact, finding all the patient stories on the hospitals' websites was not possible for the researcher given time and equipment limitations. Future research could use a web-based tool to identify all of a website's pages and which of them contain patient stories. A true random sample, then, could be selected from this population of stories.

Another limitation is that only one coder (i.e., the researcher) conducted the content analyses. Ideally, there would have been at least two coders, which would have better ensured that the collection and categorization of the data were accurate.

Having another coder would have been helpful for Content Analysis A, as the researcher found categorizing the stories into one of Hawkins' five thematic archetypes to be difficult. Not all of the stories strongly aligned themselves with one theme, while others aligned themselves with several themes. A second coder would have helped ensure that the theme chosen for each story was accurate. Future research could measure all the themes that are mentioned in a story (even those that are not the central theme) and the strength of themes in a story.

Data from Content Analysis A revealed ways that children were commonly described in the stories (e.g., normal, brave or courageous, etc.) However, the researcher developed these categories after he had collected data. For each story, he did not indicate whether the child in it fit these descriptions. Thus, the researcher cannot say that children were described predominately in one manner, nor if a hospital described children in one manner more than other hospitals did. Now that the categories have been developed, a follow-up content analysis could identify the frequency with which children were described in the stories.

While Content Analysis B provided information about whether children's hospitals were publishing patient stories on their websites' homepages, it could not demonstrate if publishing stories there was effective. Future research could attempt to develop best practices for publishing patient stories on a hospital's website, either by interviewing hospital staff who are responsible for managing the website or by examining several hospitals' website traffic data.

The interviews with communication officials provided rich, in-depth insights into how children's hospitals were crafting and publishing patient stories. However, results from this qualitative method cannot be generalized across all children's hospitals. In addition, the researcher did not ask these officials what specific goals their hospitals were trying to achieve by publishing patient stories. Examples of these goals could include increasing the hospital's

number of patients, increasing its revenue generated per patient, and increasing the number of referring pediatricians. If the researcher knew these goals, he could have seen if the patient stories were addressing them and whether they were targeting the principal audiences identified by the interview subjects (that is, prospective patients and referring providers).

A topic for future research could focus on the persuasiveness of different patient stories to prospective patients and referring providers. This research project did not set out to measure whether one type of story was more persuasive than another. But it did identify which audiences children's hospitals are trying to reach through patient stories, as well as narrative elements commonly employed in these stories. One could conduct an experiment in which parents and guardians of children with the same condition were exposed to different stories. The stories could differ by the characters who were featured and quoted, point of view, the ways children were described, and the themes that were employed. One then could measure the parents' and guardians' beliefs and attitudes toward the hospitals, as well as their intentions to choose the hospital. The same type of experiment could be conducted for referring providers. One could also conduct focus groups with these individuals that would include showing them different stories and receiving their feedback.

Future research could examine how different health care organizations (e.g., hospitals, nursing homes, pharmacies, etc.) use patient stories. And research also could look at other platforms (both print and digital) where patient stories are being shared and how effective they are at reaching their intended audiences. Several of the interview subjects noted other platforms where their hospitals publish patient stories, including Facebook, Twitter, YouTube, and Instagram. While the hospital website is a critical platform that prospective patients and referring providers visit, it is not the only one they use.

## Recommendations

Children's hospitals are using patient stories to connect with their key audiences. Two content analyses and interviews with five hospital communications officials revealed several things, including commonalities among hospital stories, narrative elements that make these stories stand out, and best practices for collecting and sharing stories. The following recommendations are addressed to children's hospital communicators and others who are looking to use stories about children to advance a health care message.

- 1. Know your audience.** Patient stories published by children's hospitals are written with a specific purpose in mind: to persuade individuals to interact with the hospital in some manner. Because of this, it's critical that you know whom you want to reach through patient stories. It likely will include prospective patients and referring providers, but it also could include donors, prospective doctor employees, and the community. Be clear on the group you want to reach, as this will impact the messages you convey and narrative elements you use.
- 2. Make sure your stories' key messages address what your audiences need.** Once you know who your audiences are, include messages in your stories that address their needs. This is why many children's hospitals are communicating *teamwork* and *compassion*. Prospective patients and referring providers are looking for sound medical advice and hope for the future. You likely will have different messages to share when communicating with donors, current patients, and the community at large.
- 3. Don't shy away from stories that highlight an illness' challenges, as these stories likely will appeal to patients and families in the midst of treatment.** While some audiences want stories that highlight a hospital's expertise and compassionate care, others

don't, in particular current patients. Break conventional ways of telling stories and be willing to use narrative elements (such as the journey theme) and tactics (such as documenting a patient's illness experience through a series of stories) that highlight the challenges an illness brings.

- 4. Focus on what makes your hospital unique—and then deploy narrative elements in your stories that reinforce this.** Unless your hospital is the Mayo Clinic and has high brand recognition, your hospital likely will blend in with others in the marketplace. You have to show your target audiences what makes your hospital unique. If your hospital only provides specialized services, lean into that. If your hospital provides a broad range of services, share stories that feature departments, medical providers, or other things that make your hospital stand out, and then use narrative elements to reinforce your message. Want to showcase your hospital's cutting-edge cancer treatments? Then compose stories that use the *battle* theme and that are full of quotes from your medical personnel. Have a medical provider whose magnetic personality endears her to every family she meets? Then consider introducing her to prospective patients through a video, making sure to ask her questions that reveal her personality and why she loves caring for patients.
- 5. Let kids be kids by having their personalities shine through your stories.** There are lots of ways you can describe the protagonists of your stories, and you'll want to make sure the characteristics you highlight align with your story's message and your hospital's brand. But don't forget to let the children's personalities shine through. Not only does it respect them, it makes your stories more authentic.
- 6. Be open to experimenting with different media channels and narrative elements, but know that human factors likely will limit your ability to do so.** The sky's the limit



with how you can craft and share an engaging patient story. You might try sharing one that's narrated by a patient or her parents, or you could gather some pictures that tell the tale and share them one-by-one on Facebook. You could even chronicle a family's hospital journey through video, getting footage throughout the stages of the Cancer Control Continuum like Children's Minnesota does. Know, however, that human factors may limit your ability to pursue these ideas. Some individuals express themselves well orally, but aren't able to do so in writing. And others might have an exceptional story that's made for the screen, but they clam up when in front of a camera. Cast a wide net as you gather story ideas, and be ready to help patients and their families share their experiences.

- 7. Use your hospital's digital team to place your patient stories where they'll be picked up by your audiences.** Your hospital's patient stories need to be findable by your audiences. So rely on your digital team to help you make smart decisions for where they should reside. They should be linkable from the homepage, but it's OK to link to a list of stories. Be sure, though, that they're at the top of this list, not buried halfway down it as is the case with Shriners Hospitals. And don't forget to have the stories appear on disease- and specialty-specific pages on your website.

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## Appendix 1 — Descriptions of Children’s Hospitals Analyzed

The following are the six children’s hospitals that were analyzed for Content Analyses A and B.

- 1. Children’s Minnesota (Minneapolis, Minnesota):** Founded in 1924, Children’s Minnesota provides care to tens of thousands of children each year in a variety of situations, including cancer treatment, diabetes management, birthing and neonatal services, and regular checkups (Children’s Minnesota, n.d.). The nonprofit is “the seventh-largest freestanding children’s healthcare organization in the U.S.,” with hospitals in Minneapolis and St. Paul and clinic locations in 14 Twin Cities suburbs (Children’s Minnesota, n.d.).
- 2. Gillette Children’s Specialty Healthcare (St. Paul, Minnesota):** Founded in 1897, Gillette Children’s Specialty Healthcare provides care to children with rare and complex musculoskeletal and neurological conditions, including cerebral palsy, neuromuscular disorders, scoliosis, and craniosynostosis (Gillette Children’s, n.d.b; Gillette Children’s, n.d.c). Its staff serves more than 25,000 children each year at the hospital’s headquarters in St. Paul and at 16 clinics throughout Minnesota (Gillette Children’s, n.d.b; Gillette Children’s, n.d.a).
- 3. Mayo Clinic Children’s Center (Rochester, Minnesota):** The Mayo Clinic is known throughout the world for its exceptional medical care, education, and research (Mayo Foundation, 2018, p. 2). Ranked best hospital in the nation by U.S. News & World Report for 2017–2018, the Mayo Clinic served 1.3 million people from all U.S. states and 136 countries in 2017 (Mayo Foundation, 2018, pp. 5, 2). Its Children’s Center in Rochester admits about 110 patients daily and is one of the top-ranked children’s



hospitals in Minnesota, the Dakotas, and Iowa (U.S. News & World Report, n.d.; Mayo Clinic, n.d.).

- 4. Shriners Hospitals for Children (Tampa, Florida):** Founded by the Shriners International fraternity, the Shriners Hospitals for Children health care system opened its first hospital in 1922 (Shriners Hospitals, n.d.). Today, its 22 hospitals in Canada, Mexico, and the U.S. (including one in Minneapolis, Minnesota) serve children who “have orthopaedic [sic] conditions, burns, spinal cord injuries, cleft lip or palate, [and] ... other complex surgical needs” (Shriners Hospitals, n.d.).
- 5. University of Minnesota Masonic Children’s Center (Minneapolis, Minnesota):** A member of the Fairview Health System, the University of Minnesota Masonic Children’s Center provides a “broad range of primary and specialty care services for infants, children, teenagers and young adults” (University of Minnesota, n.d.a). In 2015, it was recognized by U.S. News & World Report for its specialties in cancer, diabetes and endocrinology, gastroenterology and GI surgery, neonatology, and nephrology (Staff writer, 2015). As an academic research institution, it partners with staff at the university to “develop new health technologies and treatment approaches” (University of Minnesota, n.d.b).
- 6. Children’s Hospital of Wisconsin (Milwaukee, Wisconsin):** Founded in 1892, the Children’s Hospital of Wisconsin is an independent nonprofit that consists of two hospitals and several clinics across Wisconsin that serve thousands of children each year in more than 70 medical specialties (Schneider & Macey, 2004, p. 15; Children’s Hospital of Wisconsin, 2017, pp. 1-3).

## Appendix 2 — Method for Identifying Patient Stories

The researcher completed the following steps to identify patient stories for Content Analysis A.

1. Identify the hospitals' homepage URLs. The homepage URLs for the six hospitals are the following:

- **Children's Minnesota:** <https://www.childrensmn.org/>
- **Gillette Children's Specialty Healthcare:** <https://www.gillettechildrens.org/>
- **Mayo Clinic Children's Center:** <https://www.mayoclinic.org/departments-centers/childrens-center>
- **Shriners Hospitals for Children:**  
<https://www.shrinershospitalsforchildren.org/shc>
- **University of Minnesota Masonic Children's Center:**  
<https://www.mhealth.org/childrens>
- **Children's Hospital of Wisconsin:** <https://www.chw.org/>

2. Using Google, search for the following terms on each of the six hospitals' websites: story, stories, testimonial\*, patient story, patient stories, patient testimonial\*.

To conduct website-specific searches for these terms, use the following template in the Google search engine: **TERM [e.g., story, stories, testimonial\*, etc.] site:WEBSITE URL**. The following are examples:

- story site:<https://www.childrensmn.org>
- testimonial\* site:<https://www.shrinershospitalsforchildren.org/shc>
- patient stories site:<https://www.chw.org>

3. For each term for each hospital, document the webpage URLs that appear on the first page of results. This should include up to 10 results for each search.
4. Once the results for all search terms have been collected for a hospital, visit the webpage URLs.
  - If a webpage URL contains a patient story, count the URL as a story for analysis. If not, do not include it.
  - If a webpage URL contains links to multiple patient stories, count all the stories listed on that page. Record the stories' URLs.

This process will result in a collective story list, which will contain duplicate entries.

5. Review the collective story list and remove duplicate entries. This will produce the master story list for Content Analysis A.

## Appendix 3 – Coding Sheet for Content Analysis A

For each patient story, complete the following questions.

### Background Information

0. The story's web page URL (fill in)
1. Date story was reviewed (fill in date)
2. Story's website location, title, and date of publication
  - 2A. Section header (fill in)
  - 2B. Article title (fill in)
  - 2C. Date of publication (if known) (fill in date)

### Media Channel(s)

3. How is the story presented (select all that apply)?

Article with words

Photo(s)

Video

Other

### Narrative Elements

4. The story is told using the following voice (select one):

1 – First person

3 – Third person

1 & 3 – First and third person

*4B. If the story uses the first-person voice, list the narrator (fill in).*

5. The following individuals are mentioned in the story, but are not quoted and do not speak (select all that apply):

Patient

Patient's mother

Patient's father

Other family members

Medical personnel (an individual who provides medical care, e.g., doctor, nurse)

Other (fill in)

6. The following individuals are quoted (text based) or speak (video and audio based) in the story (select all that apply):

Patient

Patient's mother

Patient's father

Other family members

Medical personnel (an individual who provides medical care, e.g., doctor, nurse)

Other (fill in)

7. The story addresses the following stage(s) of the Cancer Control Continuum (select all that apply):

Prevention

Detection

Diagnosis

Treatment

Survivorship

8. The following theme(s) are present in the story (select one):

Regeneration

Illness as a battle

Athletic ideal

Journey into a distant country

Healthy-mindedness

Other and/or notes (fill in)

### **Story Summary & Miscellaneous Items**

9. The patient story contains a “call to action” (e.g., sign up for an appointment, donate) (select one).

Yes

No

*9B. If response to question 9 is “yes,” list the call to action (fill in).*

10. Summarize the story, using quoted material as appropriate (fill in).

11. Miscellaneous comments, if needed (fill in)

## Appendix 4 – Patient Story Numbers and Corresponding Web Page URLs

Patient Story Number	Patient Story URL
1	<a href="https://www.childrensmn.org/2014/06/16/gavin-vs-joe-bully/">https://www.childrensmn.org/2014/06/16/gavin-vs-joe-bully/</a>
2	<a href="https://www.childrensmn.org/2014/06/16/gavin-vs-joe-bully/">https://www.childrensmn.org/2014/06/16/gavin-vs-joe-bully/</a>
3	<a href="https://www.childrensmn.org/2014/11/27/family-thankful-for-care-infant-daughter-received-at-childrens/">https://www.childrensmn.org/2014/11/27/family-thankful-for-care-infant-daughter-received-at-childrens/</a>
4	<a href="https://www.childrensmn.org/2015/10/28/vitos-superhero-spirit/">https://www.childrensmn.org/2015/10/28/vitos-superhero-spirit/</a>
5	<a href="https://www.childrensmn.org/2015/03/17/baby-george-thrives-after-stroke-at-birth/">https://www.childrensmn.org/2015/03/17/baby-george-thrives-after-stroke-at-birth/</a>
6	<a href="https://www.childrensmn.org/2015/10/05/minnesota-boy-born-with-imperfect-heart/">https://www.childrensmn.org/2015/10/05/minnesota-boy-born-with-imperfect-heart/</a>
7	<a href="https://www.childrensmn.org/2015/11/10/lucias-joy/">https://www.childrensmn.org/2015/11/10/lucias-joy/</a>
8	<a href="https://www.childrensmn.org/2016/03/11/midwest-fetal-care-center/">https://www.childrensmn.org/2016/03/11/midwest-fetal-care-center/</a>
9	<a href="https://www.childrensmn.org/2016/11/21/kathleen-rises-above-disorders/">https://www.childrensmn.org/2016/11/21/kathleen-rises-above-disorders/</a>
10	<a href="https://www.childrensmn.org/2017/02/18/williams-surgery/">https://www.childrensmn.org/2017/02/18/williams-surgery/</a>
11	<a href="https://www.childrensmn.org/2017/03/03/baby-ingrid-genetic-diabetes/">https://www.childrensmn.org/2017/03/03/baby-ingrid-genetic-diabetes/</a>
12	<a href="https://www.childrensmn.org/2017/09/13/jacqueline/">https://www.childrensmn.org/2017/09/13/jacqueline/</a>
13	<a href="https://www.childrensmn.org/educationmaterials/teens/article/12978/asthma-monicas-story-video/">https://www.childrensmn.org/educationmaterials/teens/article/12978/asthma-monicas-story-video/</a>
14	<a href="https://www.childrensmn.org/2016/01/30/julias-journey/">https://www.childrensmn.org/2016/01/30/julias-journey/</a>
15	<a href="https://www.childrensmn.org/educationmaterials/teens/article/14520/dwarfism-emilys-story-video/">https://www.childrensmn.org/educationmaterials/teens/article/14520/dwarfism-emilys-story-video/</a>
16	<a href="https://www.gillettechildrens.org/khm/after-scoliosis-treatment-avital-aims-to-help-other-kids">https://www.gillettechildrens.org/khm/after-scoliosis-treatment-avital-aims-to-help-other-kids</a>
17	<a href="https://www.gillettechildrens.org/khm/a-girl-a-bike-and-a-dream">https://www.gillettechildrens.org/khm/a-girl-a-bike-and-a-dream</a>
18	<a href="https://www.gillettechildrens.org/khm/a-girl-a-bike-and-a-dream">https://www.gillettechildrens.org/khm/a-girl-a-bike-and-a-dream</a>
19	<a href="https://www.gillettechildrens.org/khm/a-legacy-of-strength-and-smiles">https://www.gillettechildrens.org/khm/a-legacy-of-strength-and-smiles</a>
20	<a href="https://www.gillettechildrens.org/khm/ava-approaches-rare-bone-disorder-with-bravery">https://www.gillettechildrens.org/khm/ava-approaches-rare-bone-disorder-with-bravery</a>
21	<a href="https://www.gillettechildrens.org/khm/cassidy-stands-for-her-team">https://www.gillettechildrens.org/khm/cassidy-stands-for-her-team</a>
22	<a href="https://www.gillettechildrens.org/khm/cassidy-stands-for-her-team">https://www.gillettechildrens.org/khm/cassidy-stands-for-her-team</a>
23	<a href="https://www.gillettechildrens.org/khm/family-makes-700-mile-journey-to-treat-daughters-cerebral-palsy">https://www.gillettechildrens.org/khm/family-makes-700-mile-journey-to-treat-daughters-cerebral-palsy</a>
24	<a href="https://www.gillettechildrens.org/khm/girl-scouts-greatest-achievement-is-being-a-kid">https://www.gillettechildrens.org/khm/girl-scouts-greatest-achievement-is-being-a-kid</a>
25	<a href="https://www.gillettechildrens.org/khm/its-not-career-its-a-calling-bringing-my-son-home">https://www.gillettechildrens.org/khm/its-not-career-its-a-calling-bringing-my-son-home</a>
26	<a href="https://www.gillettechildrens.org/khm/limb-lengthening-and-perseverance-give-katelyn-momentum">https://www.gillettechildrens.org/khm/limb-lengthening-and-perseverance-give-katelyn-momentum</a>

- 27 <https://www.gillettechildrens.org/khm/muscular-dystrophy-diagnosis-cant-stop-these-twins>
- 28 <https://www.gillettechildrens.org/khm/walker-overcomes-craniosynostosis>
- 29 <https://www.gillettechildrens.org/khm/my-gillette-story-by-shelley-potter>
- 30 <https://www.gillettechildrens.org/khm/not-just-brothers-best-friends>
- 31 <https://www.gillettechildrens.org/khm/saving-ahriana-after-near-tragic-accident>
- 32 [https://intheloop.mayoclinic.org/2016/05/03/my-doctor-is-my-hero-first-grader-tells-classmates/?\\_ga=2.28388860.1525854247.1523717968-827375668.1521999910](https://intheloop.mayoclinic.org/2016/05/03/my-doctor-is-my-hero-first-grader-tells-classmates/?_ga=2.28388860.1525854247.1523717968-827375668.1521999910)
- 33 [https://intheloop.mayoclinic.org/2016/05/19/tutu-tuesday-helps-take-the-sting-out-of-young-cancer-patients-treatments/?\\_ga=2.28388860.1525854247.1523717968-827375668.1521999910](https://intheloop.mayoclinic.org/2016/05/19/tutu-tuesday-helps-take-the-sting-out-of-young-cancer-patients-treatments/?_ga=2.28388860.1525854247.1523717968-827375668.1521999910)
- 34 [https://intheloop.mayoclinic.org/2016/05/26/ten-years-countless-prayers-many-headlines-one-awesome-team-two-amazing-girls/?\\_ga=2.71396435.1525854247.1523717968-827375668.1521999910](https://intheloop.mayoclinic.org/2016/05/26/ten-years-countless-prayers-many-headlines-one-awesome-team-two-amazing-girls/?_ga=2.71396435.1525854247.1523717968-827375668.1521999910)
- 35 [https://intheloop.mayoclinic.org/2016/05/26/ten-years-countless-prayers-many-headlines-one-awesome-team-two-amazing-girls/?\\_ga=2.71396435.1525854247.1523717968-827375668.1521999910](https://intheloop.mayoclinic.org/2016/05/26/ten-years-countless-prayers-many-headlines-one-awesome-team-two-amazing-girls/?_ga=2.71396435.1525854247.1523717968-827375668.1521999910)
- 36 [https://intheloop.mayoclinic.org/2016/11/03/doctors-dance-with-patient-at-her-wedding-17-years-after-saving-her-life/?\\_ga=2.230761695.1525854247.1523717968-827375668.1521999910](https://intheloop.mayoclinic.org/2016/11/03/doctors-dance-with-patient-at-her-wedding-17-years-after-saving-her-life/?_ga=2.230761695.1525854247.1523717968-827375668.1521999910)
- 37 [https://intheloop.mayoclinic.org/2017/02/07/students-rally-around-classmate-after-her-heart-transplant/?\\_ga=2.264440143.1525854247.1523717968-827375668.1521999910](https://intheloop.mayoclinic.org/2017/02/07/students-rally-around-classmate-after-her-heart-transplant/?_ga=2.264440143.1525854247.1523717968-827375668.1521999910)
- 38 <https://newsnetwork.mayoclinic.org/discussion/926-treating-more-than-the-disease-giving-kids-with-cancer-brighter-tomorrows/>
- 39 <https://newsnetwork.mayoclinic.org/discussion/926-treating-more-than-the-disease-giving-kids-with-cancer-brighter-tomorrows/>
- 40 <https://newsnetwork.mayoclinic.org/discussion/julia-fulmers-story-beating-cancer-like-a-rock-star/>
- 41 <https://newsnetwork.mayoclinic.org/discussion/julia-fulmers-story-beating-cancer-like-a-rock-star/>
- 42 [https://sharing.mayoclinic.org/2016/07/23/all-we-want-is-for-evie-to-reach-her-potential/?\\_ga=2.258106570.1525854247.1523717968-827375668.1521999910](https://sharing.mayoclinic.org/2016/07/23/all-we-want-is-for-evie-to-reach-her-potential/?_ga=2.258106570.1525854247.1523717968-827375668.1521999910)
- 43 [https://sharing.mayoclinic.org/2017/04/13/keen-expertise-helps-infant-survive-rare-life-threatening-brain-tumor/?\\_ga=2.59444077.1525854247.1523717968-827375668.1521999910](https://sharing.mayoclinic.org/2017/04/13/keen-expertise-helps-infant-survive-rare-life-threatening-brain-tumor/?_ga=2.59444077.1525854247.1523717968-827375668.1521999910)
- 44 <https://sharing.mayoclinic.org/2017/10/05/teen-navigates-ehlers-danlos-syndrome-with-the-help-of-clinical-genomics/>
- 45 <https://sharing.mayoclinic.org/2017/10/26/open-heart-surgery-achieves-success-without-blood-transfusions/>
- 46 [https://sharing.mayoclinic.org/2018/02/20/fetal-surgery-sets-the-stage-for-a-healthy-birth/?\\_ga=2.33120382.1525854247.1523717968-827375668.1521999910](https://sharing.mayoclinic.org/2018/02/20/fetal-surgery-sets-the-stage-for-a-healthy-birth/?_ga=2.33120382.1525854247.1523717968-827375668.1521999910)



- 47 [https://sharing.mayoclinic.org/2017/03/01/after-years-of-pain-a-clear-diagnosis-restores-a-teens-life/?\\_ga=2.264440143.1525854247.1523717968-827375668.1521999910](https://sharing.mayoclinic.org/2017/03/01/after-years-of-pain-a-clear-diagnosis-restores-a-teens-life/?_ga=2.264440143.1525854247.1523717968-827375668.1521999910)
- 48 <https://www.mayoclinic.org/departments-centers/childrens-center/pediatric-cardiology/overview>
- 49 <https://sharing.mayoclinic.org/2018/03/14/defying-odds-to-make-it-through-to-a-heart-lung-transplant/>
- 50 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/tiannis-story-25>
- 51 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/shriners-hospitals-patient-with-cerebral-palsy-bec-3>
- 52 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/music-therapy-for-children-kechi-okwuchis-story-21>
- 53 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/lexington-shriners-medical-center-patient-graduate-12>
- 54 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/kara39s-story-7>
- 55 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/jalen39s-story-6>
- 56 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/fashion-designer-gives-back-4>
- 57 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/claudias-story-the-trip-of-a-lifetime-18>
- 58 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/brothers-motivate-each-other-to-success--2>
- 59 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/alyssias-story-13>
- 60 <https://www.shrinershospitalsforchildren.org/shc/meet-juliana>
- 61 [https://www.shrinershospitalsforchildren.org/shc/madelyn\\_bio](https://www.shrinershospitalsforchildren.org/shc/madelyn_bio)
- 62 <https://www.shrinershospitalsforchildren.org/shc/kileestory>
- 63 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/nias-story-22>
- 64 <https://www.shrinershospitalsforchildren.org/shc/why-were-here/sols-story-24>
- 65 <https://www.mhealth.org/childrens/blog/2016/december-2016/for-liver-transplant-patient-music-therapy-makes-all-the-difference>
- 66 <https://www.mhealth.org/childrens/blog/2016/february-2016/life-affirming-photography-exhibit-opens-at-masonic-childrens-hospital>
- 67 <https://www.mhealth.org/childrens/blog/2016/june-2016/heart-surgery-helps-3-year-old-enjoy-life-with-adoptive-mom>
- 68 <https://www.mhealth.org/childrens/blog/2016/june-2016/rileys-diaversary-celebration-honors-the-hard-work-he-does-to-manage-diabetes>

- 69 <https://www.mhealth.org/childrens/blog/2016/november-2016/exercise-is-key-for-new-pediatric-cancer-program-university-of-minnesota-masonic-childrens-hospital>
- 70 <https://www.mhealth.org/childrens/blog/2016/september-2016/rare-form-epilepsy-wont-keep-mom-daughter-from-running-twin-cities-marathon>
- 71 <https://www.mhealth.org/childrens/blog/2017/april-2017/after-scary-start-with-hemangiomas-willow-living-ordinary-life>
- 72 <https://www.mhealth.org/childrens/blog/2017/april-2017/masonic-childrens-hospital-specialists-treat-leos-rare-skin-condition>
- 73 <https://www.mhealth.org/childrens/blog/2017/june-2017/cancer-patient-becomes-honorary-nurse-in-training>
- 74 <https://www.mhealth.org/childrens/blog/2017/march-2017/coordinated-care-helped-iain-beat-back-life-threatening-mssa-infection?platform=hootsuite>
- 75 <https://www.mhealth.org/childrens/blog/2017/october-2017/jennifer-mcvean-draws-from-personal-experience-to-treat-type-1-diabetes>
- 76 <https://www.mhealth.org/childrens/blog/2018/february-2018/after-long-search-for-answers-family-finds-expert-care-for-rare-disease>
- 77 <https://www.mhealth.org/childrens/blog/2018/february-2018/perspectives-photo-project-offers-life-affirming-view-into-lives-of-hospitalized-families>
- 78 <https://www.mhealth.org/childrens/blog/2018/march-2018/bone-marrow-transplant-recipient-dedicates-life-to-helping-others>
- 79 <https://www.chw.org/medical-care/neuroscience/patient-stories/cendreannas-story>
- 80 <https://www.chw.org/medical-care/neonatology/nicu/milwaukee-nicu/patient-story/nicu-nurses-recognition>
- 81 <https://www.chw.org/medical-care/craniofacial-disorders/patient-stories/mia-story>
- 82 <https://www.chw.org/medical-care/craniofacial-disorders/patient-stories/nora-story>
- 83 <https://www.chw.org/medical-care/fetal-concerns-center/patient-stories/madelyn>
- 84 <https://www.chw.org/medical-care/fetal-concerns-center/patient-stories/miles-donnerbauer>
- 85 <https://www.chw.org/medical-care/fetal-concerns-center/patient-stories/paisley>
- 86 <https://www.chw.org/medical-care/genetics-and-genomics-program/patient-stories>
- 87 <https://www.chw.org/medical-care/herma-heart/patient-stories/avas-story>
- 88 <https://www.chw.org/medical-care/herma-heart/patient-stories/gavins-story>
- 89 <https://www.chw.org/medical-care/imaging/why-choose-us/patient-stories>
- 90 <https://www.chw.org/medical-care/neuroscience/patient-stories/adam-story>

- 91 <https://www.chw.org/medical-care/neuroscience/patient-stories/emilys-story>
- 92 <https://www.chw.org/medical-care/orthopedics/patient-stories>
- 93 <https://www.chw.org/medical-care/sacral-neuromodulation/victorias-story>

## **Appendix 5 — Story Samples from Content Analysis A**

The following patient story samples from Content Analysis A are provided, which were collected on July 6, 2018.

- Story 9 from Children’s Minnesota (p. 100)
- Story 16 from Gillette Children’s Specialty Healthcare (p. 101)
- Story 38 from Mayo Clinic Children’s Center (p. 102)
- Story 52 from Shriners Hospitals for Children (p. 103)
- Story 69 from the University of Minnesota Masonic Children’s Center (p. 104)
- Story 80 from the Children’s Hospital of Wisconsin (p. 105)



## CHILDREN'S STORIES



#AMAZINGIS STORIES, MIGHTY BLOG

# Kathleen rises above her uncommon combination of disorders

By Kathleen, Children's Minnesota patient



In the summer of 2015, I was dealing with two disorders that had worked their way into my life – anorexia nervosa, an eating disorder characterized by inadequate caloric intake, and postural orthostatic tachycardia syndrome (POTS), a condition that involves a dangerously rapid heartbeat, with symptoms like migraines and dizziness.

Because of the unique combination of the two disorders, I was in constant pain – I had difficulty getting out of bed in the morning, and I could barely eat or drink anything. I had terrible headaches and was always lightheaded. I lost a large amount of muscle mass and my body constantly felt weak. I even endured seven stress fractures, which left me in a wheelchair. My autonomic nervous system was failing, and my heart was suffering. With POTS, blood does not flow freely to the vital organs, which made my heart and stomach have trouble functioning. I was physically and emotionally unable to eat. As I was losing muscle mass, my heart was getting weaker, complicating my blood circulation and disrupting my pulse and blood pressure. Essentially, my body was shutting down.

That July, I was admitted to the Center for the Treatment of Eating Disorders Clinic at Children's Minnesota. Before I came to Children's, having not yet been diagnosed with POTS, I tried other treatment methods and programs, but nothing was working for me. I was scared that I would never get the help I knew I needed. I became discouraged and pessimistic, and I had lost nearly all hope.

My first day being treated at Children's Minnesota, my care team sat down with me and asked, "What is it going to take for you to get better?" I told them it would take a miracle.

"Okay," they responded. "We'll be your miracle."

From that moment on, everything changed for me. For the first time in a long time, I felt hopeful. The environment at Children's made me feel different, inspired. In the past, I was worried I would be stigmatized by having an eating disorder and treated differently from patients suffering from other illnesses or injuries. But at Children's, it doesn't matter if you have diabetes, cancer, an eating disorder or any other illness – everyone is treated with the same compassion and respect. Children's believed I could be amazing again.

Over the course of the next year, I worked with several different care providers from the Center for the Treatment of Eating Disorders; the Children's Heart Clinic; the Pain, Palliative and Integrative Medicine Clinic and more. When I was in the hospital, my doctors and nurses became – and still are – my team. "We've got your back," they always said. And they always did.

Still, treatment was extremely challenging. I underwent weekly IV infusions for my POTS, trying to minimize headaches and stomach pain, while continuing the re-feeding process. I have spent countless hours in the Pain, Palliative and Integrative Medicine Clinic, engaging in biofeedback exercises, relaxation and coping strategies.

Since coming to Children's, the doctors, nurses and staff in every capacity have gone out of their way to make me and my family feel comfortable. From my nurses sitting with me during the night while I couldn't sleep, to arm-wrestling my doctors, Children's has become my second home. One of my doctors in the hospital told me, "We're going to do a lot of things that will make you feel uncomfortable, but I promise, we won't hurt you." Together, we were determined to beat these illnesses – whatever it would take.



During treatment, I was so thankful that I had such a great support system by my side at all times – my family. My family, including my sisters, were there for me every step of the way, and I know I wouldn't be where I am today without their constant love and encouragement.

"After Kathleen's diagnosis, we were treading on uncommon ground – we didn't know how we were supposed to feel, what we were supposed to think or what we could do to help," my mom said. "It's a difficult thing to go through as a family, but we knew Kathleen was in the best hands, and everyone at the hospital supported us – all of us. They made the whole family feel like all our questions, concerns and comments truly mattered."

Because of the unique combination of my disorders, I didn't know anyone else personally who had gone through a similar struggle, so I didn't have anyone to look to as an example for guidance. But my care team gave me someone to look up to – myself. They encouraged me to be my own hero, to set a positive example for others who would follow in my path. So I did. There were several other patients I met and bonded with in the hospital, and I hope that I am able to serve as a role model for them and other patients after them. It is my hope for other children and their families to see my story and discover the hope we found at Children's.

Children's Minnesota truly was my miracle. They saved my life. My journey is not over and some days are still a challenge, but I am continuing to move forward. I have grown so much as a person this last year, and I am confident that with the support of my family, friends and care team, I will be able to handle anything that comes my way. And the best part? I know that Children's always has my back.



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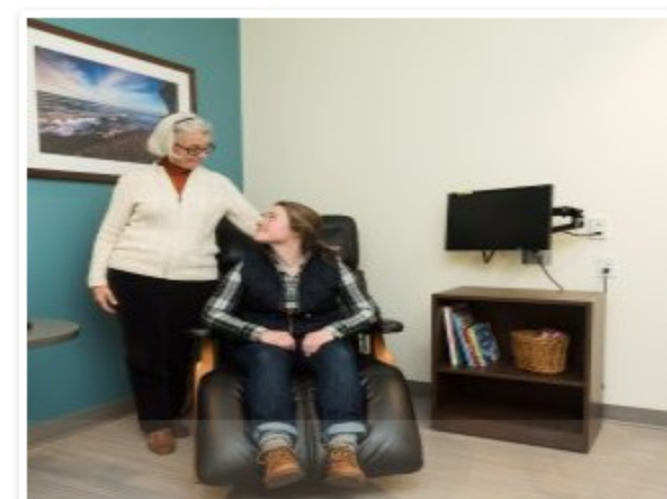
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# After Scoliosis Treatment, Avital Aims to Help Other Kids

Home / Kids Health Matters / After Scoliosis Treatment, Avital Aims to Help Other Kids

By Lina Abdennabi  
June 23, 2017

It's 2015, and Avital Harris is out on a walk with her family. It's a hot day. Too hot frankly, and she's had about enough. Some combination of the heat and playful aggravation that only a little brother can elicit overwhelms her. She loses it.

"I took off my back brace and literally threw it as hard as I could into the woods," Avital recounts while laughing. "I said, 'You can get it,' and walked away. It wasn't my finest hour."

Such behavior between a 13-year-old and a younger sibling is certainly not a novel concept, but more than teenage angst played a role in this equation. At the time, Avital had been recently diagnosed with scoliosis. She had received a brace to attempt to halt the increasing curvature of her spine, and while effective, it was cumbersome.

"It's Minnesota in the summer," Avital says. "You want to get out and enjoy the weather, and sometimes having the brace made that a little harder to do. I didn't always handle it very well."



## A Surprising Diagnosis

**Adolescent idiopathic scoliosis** (AIS) is by far the most common form of scoliosis, affecting children between ages 10 to 18; it's found in as many as four in 100 adolescents. While heredity may be a factor, the cause of AIS is unknown. It can happen to any child.

Avital's pediatrician discovered her scoliosis during a routine checkup and referred her to spine surgeon **Tenner Guillaume**, MD, at Gillette Children's Specialty Healthcare.

"When you've been healthy your whole life, it can be kind of jarring to have something like this happen to you," Avital recalls. "When Dr. Guillaume said that my spine curvature came right up to the point of requiring surgery, I thought, 'This can't be happening.' I was freaking out."

## Looking on the Bright Side

Despite the anxiety and fear that accompanied her diagnosis, Avital also felt relieved: Her pediatrician had caught her scoliosis just in time to avoid surgery. Instead, she could wear a back brace. "The process seemed a lot less scary and would allow me to remain flexible in the long-term so that I can play sports. My friend had a brace before, so I was more familiar with it."

At Gillette, Avital was fitted with a brace after being casted in different standing positions to ensure comfort. The fun part came when she had the chance to pick a design for her brace. She opted for the New Orleans Saints logo, in honor of her father's hometown. A week later, Avital received her brace and started wearing it 20 hours each day in an effort to correct her spine curvature.



The careful and comprehensive approach that addressed all of her possible treatment options made Avital's experience at Gillette special, as she explains. "Everyone that I met made me feel like my opinion was important. They planned my treatment around what my goals were, and made sure all of my questions were answered before moving forward. It was really important to my doctors that I understood everything that was going on."

As an added bonus, she says, "I learned a lot of new vocabulary from sitting in appointments with Dr. Guillaume and my parents."

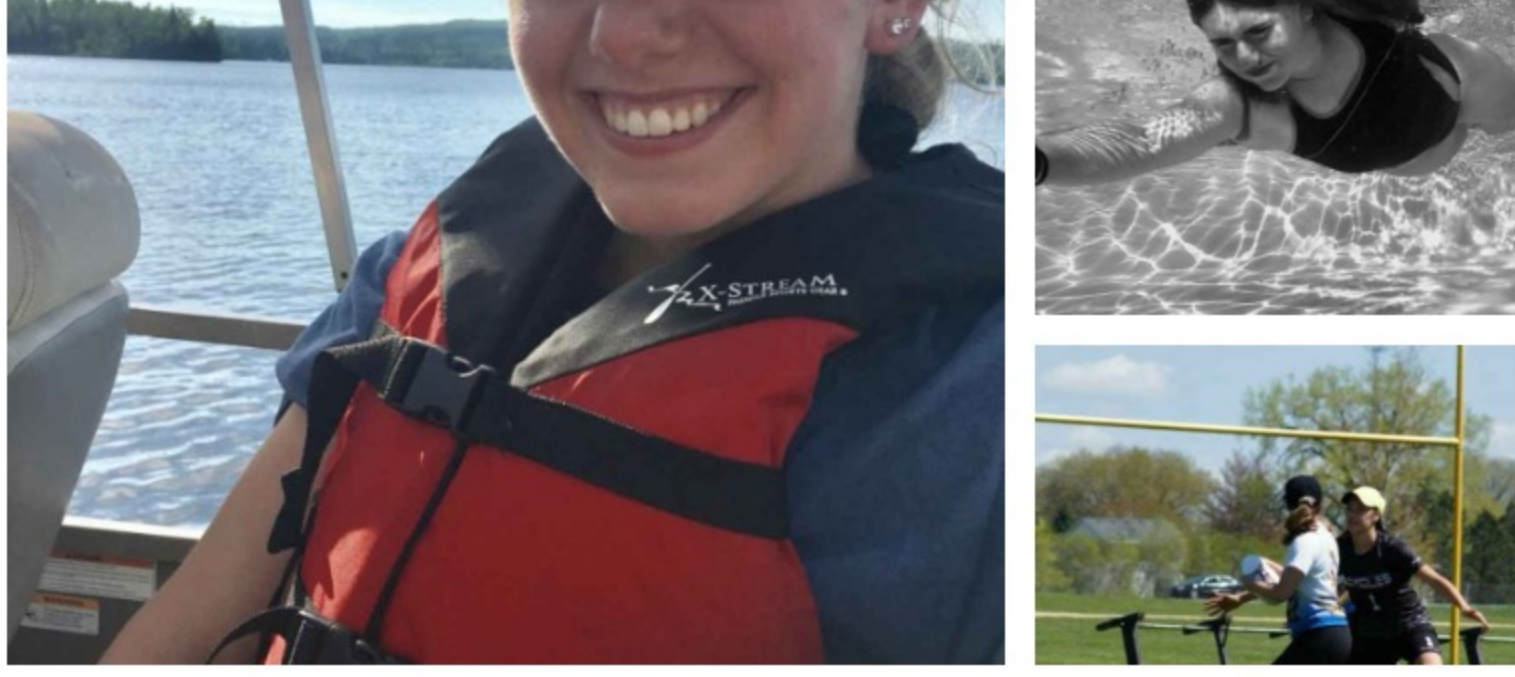
Avital's experience at Gillette also altered her perspective on life. "Most of the patients I met were younger than me, and many of them had more serious conditions," she explains. "They were working to overcome so many obstacles yet remained full of life and happiness. The courage I saw every day was inspiring; it encouraged me to always look on the bright side and not let my condition stop me from achieving my goals."

## 'It's Not So Bad!'

Although going back to school wearing a brace wasn't necessarily a concern for Avital because it would barely be noticeable underneath her clothes, she admits, "I wasn't looking forward to explaining why my back was so hard when friends would hug me, or why I had such perfect posture all the time. I would wear huge sweaters so that nobody would be able to detect it."

Getting used to sleeping in her brace soon began to feel natural for Avital, and the few hours a day that she didn't need to wear it, she would go swimming. As she got used to wearing it every day, Avital describes it as more annoying than anything else. "My friends would try my brace on and tell me 'It's not so bad.' But I'm sure they wouldn't say that if they wore it for 20 hours a day, especially in the summer!"

Aside from the genuine curiosity from friends and family, Avital didn't appreciate people feeling sorry for her because of her scoliosis. It didn't feel right, because Avital knew she was going to be OK. She didn't see herself any differently than others, and did not want to be treated as such.



## No More Oversized Clothing

Besides being an active swimmer and a basketball and ultimate Frisbee player, Avital is also a young entrepreneur in-the-making. At just 15 years old she is already working on a business plan to develop a clothing line that will accommodate kids who wear braces. "Scoliosis is very common—a lot of people have to wear a brace, and I don't think it's fair for anyone to struggle to find clothing that fits and is still flattering," she says.

After two years of wearing her brace nearly 24 hours a day, Avital's Gillette team had happy news—she could begin to phase it out. She began with not wearing it to school, then only during sleep. Now, as she gets ready to enter her sophomore year of high school, Avital is excited that she doesn't need to wear her brace anymore. The curvature in her spine that once reached 45 degrees now sits in the low 30s, and Avital is eager to transform her experience into change.

"I want kids who have scoliosis to know that they don't need to feel afraid or ashamed about their brace and condition. I want them to know that even though committing to wearing a brace all the time is hard work, it will pay off and they will be just fine."

SPINE BRACING IDIOPATHIC SCOLIOSIS

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By Ian Roth

# Treating more than the disease: Giving kids with cancer Brighter Tomorrows

September 26, 2017



While survival rates continue to improve, going through treatment can be incredibly difficult for children dealing with cancer and their families. But organizations that focus on lifting the spirits of patients and their families and helping them stay positive during treatment have become a welcome part of the treatment process. Often, these organizations dramatically affect outcomes.

Connor Johnson and his family think an organization called Brighter Tomorrows that helped them keep a positive outlook during his cancer treatment is one of the main reasons the 15-year-old is now cancer-free.



Watch: Treating more than the disease: Giving kids with cancer Brighter Tomorrows

**Journalists: Broadcast-quality video pkg (7:00) is in the downloads. Read the script.**

Few 15-year-old kids are as excited to start high school as Connor Johnson was. Less than two years earlier, he and his parents didn't know if he would ever get the chance to.

"I was 13 and we went in for an eye checkup just 'cause I was having headaches," Connor Johnson says. "And I was vomiting too, so we just went in to the eye doctor to get checked. And he scheduled an MRI for the next day, and that's what diagnosed me."

The diagnosis is something no 13-year-old should ever have to worry about.

"I was pretty much in shock, because I would have never thought that I would have got cancer," says Connor Johnson. "But, yeah, I just really couldn't grasp my mind around it."

Connor Johnson had medulloblastoma, the most common form of brain cancer in children.

His parents say they were just as shocked as he was, but they had little time to consider the implications of their youngest child having cancer.

"I mean, it was – it came on so fast that there was no planning," Connor's father, Curt Johnson, says. "There was no thinking. It was just we knew we had to do it, you know, to try to save his life. So we just went in with the mindset of, OK, one step at a time. Brain surgery."

And that's how the most terrifying and painful time in the Johnsons' life began.

"Well, the brain surgery, I think it was six hours. And after that, I think a couple weeks later, I went to proton beam," Connor says. "And we did 30 sessions of that. And then after that we did chemo for 46 weeks, and we'd go, like, every week for that. And it's been pretty tough, but [I've] gotten through it."

But there were times Connor Johnson questioned whether he could get through it.

"Well, going into surgery, they said it was, like, a 1 percent chance of dying. And at that time, I thought that I could – I could die," Connor Johnson says. "But I haven't really thought that I was going to die. I thought that I'd get through it, but I was – I was never sure."

Fear of the odds, however small, loomed large for Connor Johnson's parents too – even as they tried to distract him from them.

"Well, I think any parent will tell you that they'd trade places with the kids – their kid in a heartbeat," Curt Johnson says. "I mean, you wish you could be in their place and feel their – feel the pain instead of them. But it's – it's pretty emotional. You try to, you know, I used humor a lot to keep them upbeat and positive. And you try not to show your emotions and cry and stuff in front of them as much as possible, but there's times when you do. But you just try to keep an upbeat, positive attitude, and just wish for the best."

Dr. Shakila Khan is a pediatric oncologist at Mayo Clinic's Rochester, Minnesota, campus. She was part of Connor's medical team there.

She says extensive research and great participation in clinical trials have drastically improved the numbers for childhood cancer outcomes over the years. But she says doctors like her have also come a long way in learning how to treat the patient and not just the disease.

"I mean, we treat the child as a whole," Dr. Khan says. "I usually tell the parents that we are part of the same team, and are, you know, they are part of our team. It is a multidisciplinary team, and we also include them so that we can take care of the child as a whole, not only for the chemotherapy."

"And attitude makes a big difference," says Dr. Khan. "I've seen – I've been doing it for a long time. Positive attitude helps."

But staying positive while going through such a traumatic time can be difficult for the patient and the parents.

"When you hear those four words: your child has cancer, your life just comes to a screeching halt," Sherrie Decker, co-founder of Brighter Tomorrows, an non-profit that provides support and resources to families dealing with pediatric cancer treatment at Mayo Clinic, says. Matter of fact, when the doctor tells you those four words, you don't hear anything the doctor is saying for the rest of that particular conversation. Everything is a blur. It is your worst nightmare. And when all you know of cancer is death, you think immediately that's what your child is going to go through, and that's where our minds go right away. But that's not always necessarily the case."

Decker knows the experience all too well. She went through it with her daughter, Shanna, close to 20 years ago.

"It's very true that when you look out the window and you watch the rest of the world moving on, just the cars moving down the street, the people moving through the courtyard, you think 'how can they go on with their life when our life has come to an absolute standstill,'" Decker says.

She says it's a lonely time. That's why she and four other mothers of kids with cancer started Brighter Tomorrows.

"And what we learned is that even though it was hard for the parents, we had to provide that – that hope for that child, because they're always looking to the parents' eyes for that," Decker says. And, so, that's why it's really important for parents to have a place to go where they can seek re – you know, be re-energized a little bit by other families that are going through the same thing. And that's where the organization plays a big part in bringing another family into the room that's already done this and helping that family get a grasp on what they have to go through."

Brighter Tomorrows' work begins when these families need them most. The organization's first step is to provide a comfort kit full of things like snacks and toiletries they might need for long stays in the hospital, as well as some financial assistance during treatment.

They offer a safe place of understanding for parents to meet other parents, patients to meet other patients and even siblings to meet other siblings all going through the same thing.

There is a mutual understanding they can only find in others living under the same dark cloud.

"Yeah, because they'd, like, tell you their experiences, and it'd just help you through it a little bit," Connor Johnson says.

Perhaps, most importantly, Brighter Tomorrows hosts monthly events for the kids going through treatment to look forward to.

"You know, I mean, it always helps if you, you know, have things to look forward to," Dr. Khan says. "But kids are very resilient. I have to tell you, they just deal with things much better than adults."

Curt Johnson thinks Brighter Tomorrows' method of supporting families has made a profound difference for his family.

"It probably, you know, the treatments and everything would have been the same," Curt Johnson says. "But the positive mindset was definitely strengthened by going to Brighter Tomorrows and just being able to talk to other people that are going through the same thing you are – the same fears and emotions and hopes."

For Curt and Connor Johnson, it's been a daunting journey through treatment. But they have had little victories along the way to celebrate: each one making the effort to stay positive a little bit easier. They believe it was part of a cycle in which the positivity led to more victories to celebrate.

Connor Johnson made it through brain surgery. Then, after 30 sessions of cutting-edge proton beam therapy, Connor Johnson got to ring the ceremonial bell, signifying the successful completion of his specialized radiation therapy.

"It kind of surprised him how many people were there, but ringing the bell, I mean, was pretty emotional," Curt Johnson says.

Then, instead of doing things other kids his age were doing, like going to school, playing baseball, or hanging out with his friends, Connor Johnson pushed through 46 weeks of chemotherapy.

And after more than a year of treatment, Connor Johnson is now cancer-free and heading back to school with big plans for his future.

"I'm thinking of being in the medical field, and because people don't realize that life is so precious," Connor Johnson says. "And, yeah, I'm just think that I want to help people later in life."

"Grasp every day like it could be their last, because [for] a kid going through cancer, it may be their last," Curt Johnson says. "But just be positive about things. You know, hug your kid. That's first and foremost. Just hug them and love them."

[Click here to learn more about Brighter Tomorrows.](#)

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# Music therapy for children – Kechi Okwuchi's story

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On December 10, 2005, 16-year-old Kechi Okwuchi and 60 of her boarding school classmates were flying home to Port Harcourt, Nigeria, to be with their families for the holidays. After an uneventful flight, 20 minutes before landing, the plane shook with violent turbulence and slammed to the ground, killing all but two of its 109 passengers. Kechi was one of the two who survived.

She awoke, five weeks later, in a South African hospital with third degree burns over 65 percent of her body. She spent seven months there, fighting to survive. Two years after the accident, officials at Shell Hospital, Nigeria, contacted Shriners Hospitals for Children — Galveston about her injuries, knowing the hospital's international reputation for saving and transforming the lives

of children from all over the world who have been severely burned.

Kechi arrived at the Galveston Shriners Hospital in March 2007. Since then, she has had more than 100 surgeries, including releases of burn scar contractures, skin grafts, web space deepening and ear reconstruction.

Fast forward to 2017, and Kechi is getting an emotional standing ovation from the large audience for her powerful performance of Ed Sheeran's Thinking Out Loud for a national TV show. Shriners Hospitals for Children helped her get there.

Treatment and care for children goes far beyond surgeries at the Galveston Shriners Hospital. Counseling and therapies to improve movement and foster emotional growth are all part of the hospital's care to help children gain and build confidence. All of these, such as music therapy, are designed to help children cope and thrive emotionally with surviving such tragedies and living with extreme changes in their appearance. Music therapy was a big part of Kechi's treatment during her time at Shriners Hospitals for Children.

Regular visits from the hospital's music therapist gave her inspiration to fight and survive, she says. She eventually performed a concert for her fellow patients, her first time singing for an audience.

"Singing is what helped me survive," says Kechi. "Music helped me pull through all the emotions of surviving the crash and through all the surgeries and recovery."

In addition to the personal, specialized care and the quality and dedication of the staff, Shriners Hospitals is unique because it is the only place where children with large, visible burns can meet other kids with the same. This does not happen in other hospitals and it is especially comforting for kids to meet others who are going through similarly unique experiences.

"Kechi is an inspiration to other burn patients and those who provided her care," says Mary Jaco, RN, MSN, administrator at the Galveston Shriners Hospital. "It's very difficult work, but it's worth it, especially when you meet patients like Kechi who not only thrive, but return to the hospital to encourage and inspire other patients."

In addition to being a talented singer, Kechi graduated in 2015 from the University of St. Thomas with a degree in economics and gave a speech during her commencement ceremony. She is currently in graduate school at the University of St. Thomas pursuing an MBA in economics. After graduation, her dream is to work for the United Nations or Federal Reserve.

"Kechi is especially inspiring because she had so many emotional burdens to shoulder," says Jaco. "Kechi, like so many of our patients, has amazing strength," she adds. "She goes from being a young lady succeeding in school, to surviving a plane crash and going through the physical and emotional aspects of recovery, as well as exploring why she survived the crash. Her appearance completely changes and she has to learn again to do things she used to do: it's all too much to imagine. When I think of Kechi, who has moved on from being afraid to go out in public and dealing with the stares because of her scars, to not only go on stage to sing in front of people, but to now take a national stage in front of huge audience, to be judged... it takes amazing internal fortitude. We are all very proud of Kechi."



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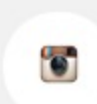
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## Exercise Is Key For A New Pediatric Cancer Program At Masonic Children's Hospital

Gus Smith worried a pediatric cancer diagnosis would keep him from playing soccer. But a new program under evaluation at University of Minnesota Masonic Children's Hospital combines traditional treatment, like chemotherapy, with a new element: exercise.



Diagnosed with Hodgkin lymphoma, Gus Smith (center) is participating in a new treatment program at University of Minnesota Masonic Children's Hospital that is studying the effect of regular exercise to help counteract the effects of chemotherapy.

**NOVEMBER 9, 2016** | By Staff Writer

For 12-year-old Gus Smith, soccer is life.

Playing all summer and into the winter, Gus surrounds himself with the sport. He has jerseys and photos and tournament towels adorned with pins from around the world—and he's already picked up season tickets for 2017 when the Minnesota United join Major League Soccer.

On May 5, Gus was diagnosed with stage IV Hodgkin lymphoma. His doctors at University of Minnesota Masonic Children's Hospital started him on a 12-week course of chemotherapy almost immediately.

A cancer diagnosis is devastating for any family, but for Gus it also meant something else: No more soccer.

"That was the big, heartbreaking part of this," said mom Jackie Smith. "Last summer he played soccer six hours every day. We knew this summer probably wouldn't look like that."

Gus's cancer hasn't stopped him—in fact it's barely slowed him down. He has continued to play soccer, encouraged by his healthcare team.

That's because the nurse practitioners at University of Minnesota Masonic Children's Hospital have received training to implement an individualized exercise program for pediatric cancer patients. The study will assess whether this coaching increases physical activity levels and subsequently has a positive effect on fatigue and mood.

And so far, it seems to be working.

"Anecdotally, we've seen less fatigue in our patients. Many patients tend to lose endurance and strength during therapy, but this program aims to preserve greater physical function. We've also seen an overall enhancement in mood," said Pediatric Nurse Practitioner Lexi Maciej, MS, RN, CNP. "I haven't seen any negative effects from kids trying to be more physically active."

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For Gus, that means he is able to be a "normal kid" again. This summer, he played with his regular soccer club, Joy of the People, an organization that prioritizes personal growth over glory. Gus even scored a goal in a tournament this summer in sweltering 100-degree heat.

"It isn't just the physical activity," Jackie said. "For Gus, soccer means being with your friends, playing again and having the support of your team."

Not all pediatric cancer patients are able to retain high levels of activity. Often, patients are limited by their specific illness or treatment regimen. If patients have a brain tumor in their arm or leg, for example, they might be limited in how they can move. A bone cancer can affect stability and balance. And for patients like Gus whose treatment can result in lowered blood counts, there's an increased risk of bleeding.

"We try to direct patients toward activities that are safe and appropriate for their treatment plan," Maciej said. "For some people it's yoga, for other kids it's going to the park and playing on the playground for 30 minutes. For those who have been sedentary, it may mean making a goal to walk around the block three times a week."

Because Gus is enrolled in a medical study examining the effects of exercise on patients, he also uses a FitBit Flex Tracker to measure how active he is. Study coordinators then use the data to measure the patient's progress. University of Minnesota School of Nursing Assistant Professor Casey Hooke, PhD, APRN, has partnered with clinical staff at the hospital to help coordinate the study.

Maciej hopes that one day all of her pediatric patients will be able to use trackers, but said the study is necessary to first understand whether using them is a worthwhile and effective approach.

Although Gus wasn't able to play on his school team this fall because of treatment, he recently finished up his second round of chemotherapy and is now looking forward to a winter season of futsal—a modified indoor soccer game played with a smaller, denser soccer ball.

While his nurse might be limited at home in the field, Gus said he just remembers the key advice his nurse practitioners gave him at the hospital: Be yourself.

**Tags:** Cancer Care; Lymphoma; Alexis Maciej, MS, RN, CNP; University of Minnesota Masonic Children's Hospital; Patient Story

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## NICU nurses recognized for compassionate care

When Dylan Collien, age 2½, had his final developmental appointment at Children's Hospital of Wisconsin and passed with flying colors, it was no surprise to his parents. Dylan is an active toddler who loves to help his mom and dad clean and cook, and adores trucks. "Dylan is perfect," says his mother, Valerie. "He's very busy and inquisitive, always learning."

You'd never guess Dylan spent the first part of his life in the [neonatal intensive care unit \(NICU\)](#) at Children's Hospital.

Valerie Collien's pregnancy was right on track when suddenly, ten weeks before her due date, she began having contractions. "I wasn't sure what I was experiencing," she said. "We went to our local hospital on a Sunday, and I was starting to dilate. They told me they were transporting me to Froedtert right away."



The birth center at Froedtert is directly located within Children's Hospital of Wisconsin in Milwaukee, and is connected to its NICU, making the transition from birth to neonatal care immediate and seamless. Valerie's doctors kept her from going into labor for nearly five days, and during that time, Children's neonatologists and other specialists came to Valerie and her husband Kerry to explain everything they needed to know about the NICU.

"We'd never thought about pre-term birth," said Valerie, "but the doctors and staff kept us informed. They made us comfortable in a situation that's not comfortable."

When Dylan was born, he weighed in at 3 lbs. 15.9 oz., and was immediately transported to the NICU. He was there for six weeks.

### Exceptional nursing

Even for a relatively uncomplicated case like Dylan's, care for premature babies involves multiple tests and a good amount of uncertainty. For Valerie, it was nurses like Karli and Sarah who made that difficult time bearable.

"They gave Dylan exceptional care," she said. "They had such a connection to him." At times when Valerie and Kerry couldn't be there, the nurses kept them involved. "They would tell us what he was doing with love in their voice. It's a gift they have, not just a job."

Dylan grew and thrived, but it was a long road. "In my mind, it was a miracle," said Valerie. "He's a strong boy, but he also got the very best care."

During those six weeks, Kerry had to go back to work, and Valerie traveled home to Fond du Lac many nights, too. "It's tough to be away from your baby when they're in the NICU. The nurses made it okay for us as parents to step aside for a few moments.

"No stone was unturned, everything that needed to be done was done. It was like having an angel by our side."

Valerie says words can't express how much the Dylan's nursing care meant to their family, but she recently showed her gratitude by nominating Dylan's nurses for a [DAISY Award](#). The Children's Hospital award recognizes extraordinary nursing knowledge and compassionate care.

### Meeting every milestone

Dylan received regular follow-up care with developmental specialist Laurel Bear, MD, a pediatric developmental specialist at Children's Hospital and a team that includes physical, occupational and speech therapists. "We absolutely loved going to those appointments," said Valerie. "We got great pointers, and learned what to keep an eye out for."

The moment Dylan "tested out" of his developmental program was bittersweet. "Every time we came back to Children's we would think 'this is where it all began,'" said Valerie. "Now I look at him and think there's no stopping him."

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## Appendix 6 — Coding Sheet for Content Analysis B

For each children’s hospital website, complete the following questions:

1. Children’s hospital name (fill in).
2. Website homepage URL (fill in).
3. Date website homepage reviewed (fill in).
4. Number of links to second-level pages found on the homepage, not counting the search function (fill in number).
5. Number of homepage links that go to a patient story or list of patient stories (fill in number).
6. For each link identified in Question 5, complete the following information:

Web page URL

Title of web page

Number of stories on web page (*if link goes directly to a patient story, write “Direct”*)

## Appendix 7 — Data Summary from Content Analysis A: Quantity of Stories that Display Narrative Elements

	Children's Minnesota	Gillette	Mayo	Shriners	U of M	Wisconsin	Total	% of Total # Stories
<b># Stories</b>	15	16	18	15	14	15	<b>93</b>	
<b># Non-Repeated Stories</b>	14	14	15	15	14	15	<b>87</b>	
<b>Content</b>								
Articles	14	14	14	15	14	15	86	92.5%
Photos	7	13	12	13	14	14	73	78.5%
Videos	9	2	4	0	1	2	18	19.4%
Other	0	1	0	0	0	0	1	1.1%
<b>Perspective</b>								
1st person	7	1	1	2	0	1	12	12.9%
3rd person	5	14	16	13	11	11	70	75.3%
1st & 3rd person	3	1	1	0	3	3	11	11.8%
<b>Character Mentioned</b>								
Patient	9	12	5	9	10	14	59	63.4%
Mother	2	3	5	7	1	1	19	20.4%
Father	6	6	5	4	7	7	35	37.6%
Other family members	8	5	6	8	5	9	41	44.1%
Medical personnel	9	14	8	11	10	13	65	69.9%
Other	6	6	3	9	1	1	26	28.0%
<b>Character Quoted</b>								
Patient	6	4	13	6	5	1	35	37.6%
Mother	10	12	11	4	12	14	63	67.7%
Father	3	1	7	0	2	4	17	18.3%
Other family members	1	0	0	0	1	0	2	2.2%
Medical personnel	5	2	13	1	11	5	37	39.8%
Other	0	0	6	2	4	0	12	12.9%

*(Continued)*

	<b>Children's Minnesota</b>	<b>Gillette</b>	<b>Mayo</b>	<b>Shriners</b>	<b>U of M</b>	<b>Wisconsin</b>		<b>Total</b>	<b>% of Total # Stories</b>
<b>Subject Matter</b>									
Prevention	0	0	0	0	1	0		1	1.1%
Detection	8	6	10	4	6	8		42	45.2%
Diagnosis	12	11	13	11	12	13		72	77.4%
Treatment	12	11	18	13	14	15		83	89.2%
Survivorship	9	11	13	12	9	14		68	73.1%
<b>Theme</b>									
Regeneration	1	0	1	2	1	3		8	8.6%
Battle	6	3	14	4	5	5		37	39.8%
Athlete	4	11	1	4	2	0		22	23.7%
Journey	3	2	0	3	4	5		17	18.3%
Healthy-Mindedness	0	0	1	1	2	0		4	4.3%
<b># Calls to Action</b>	3	4	6	3	13	0		29	31.2%