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Narrative Inquiry in Bioethics, Volume 12, Number 1, Spring 2022, pp. 53-76 (Article)

Published by Johns Hopkins University Press
DOI: *https://doi.org/10.1353/nib.2022.0017*

RESEARCH ARTICLE

Examining Illness through Pediatric Poetry and Prose: A Mixed Methods Study

Daniel H. Grossoehme[*†‡], Nicole Robinson[*‡§], Sarah Friebert[*†§], Miraides Brown[†], & Julie M. Aultman[‡]**

[*]Haslinger Family Pediatric Palliative Care Center, Akron Children's Hospital, Akron, OH, USA

[†]Rebecca D. Considine Research Institute, Akron Children's Hospital, Akron, OH, USA

[‡]Department of Family & Community Medicine, Northeast Ohio Medical University, Rootstown, OH, USA

[§]Department of Pediatrics, Northeast Ohio Medical University, Rootstown, OH, USA

[**]Emily Cooper Welty Expressive Therapy Center, Akron Children's Hospital, Akron, OH, USA

Correspondence concerning this article should be addressed to Daniel H. Grossoehme, Haslinger Family Pediatric Palliative Care Center, 1 Perkins Square, Akron, OH 44308 USA

Email: dgrossoehme@akronchildrens.org

Conflicts of Interest. The authors have no conflicts of interest to report.

Abstract. The purpose of this mixed-methods retrospective study was to characterize the linguistic and narrative properties of texts generated by hospitalized pediatric patients who are experiencing significant illnesses. These young writers voluntarily participated in a narrative intervention through a program at a children's hospital that serves diverse urban and rural populations. The primary aim was to use interpretive theoretical analysis and linguistic analysis to test the following hypotheses: (1) hospital-generated texts have linguistic characteristics consistent with texts written to improve health outcomes; (2) stories told by pediatric patients through poetry and prose can be classified using Frank's illness narrative types, serving as a starting point to situate caregivers into the pediatric writer's world in a moment in time; (3) pediatric stories are authentic stories that yield important insights about patients and their relationships with others despite lacking formal narrative elements (e.g., plot) and form.

Acknowledgments. The authors gratefully acknowledge those who made their writings available as well as Ashley Morris and Gwendolyn Richner (research coordinators), Melissa Krager (administrative assistant), and Monica Anda (chaplain).

Keywords. Pediatrics, Illness, Narrative, Poetry, Expressive Therapy

The Rulebook

My body doesn't follow the rulebook.
It fails to achieve improvement,
fails to defend itself.

When my body resists medication
and dodges all the care,
the light at the end of the tunnel
starts to disappear.

My anatomy, an exception to normality,
is flawed but still defeats all odds.
It flies beyond the hospital walls
in search of more and more healing.

My body is stronger than a rubber band
that never snaps, stronger
than steel and concrete.
My body is always denying defeat.

—Adolescent Writer

Background

Persons who have had traumatic experiences are able to understand the trauma through expressive writing, converting memories and feelings into an organized written schema (Boals, 2012; Harber & Pennebaker, 1992). One classification schema is that of the illness narrative, which can be traced back to antiquity (King, 2014). Physicians incorporated illness narratives in their patient care as early as the 17th century (Pearcy 1992, Bury 2001, Lawrence 2006). Although historically illness narratives represented the perspectives of the medical establishment instead of the patient (Frank, 1995), focus has shifted in the last few decades. The study of illness narratives, emerging with Susan Sontag's *Illness as Metaphor* (1978), and gaining momentum due to prolific authors, has made an impact in medical practice and education (Kleinman, 1988; Frank, 1995; Charon, 2007; Charon, 2017; King, 2014). This form of meaning making can elicit narrative humility among healthcare professionals through a deeper understanding of the context of their patients' experiences within and external to the clinical setting (DasGupta, 2008; Shapiro, 2011).

To date, most narrative illness studies have been conducted with adults. Published childhood illness narratives are often written by adults remembering their childhood experiences or by the parents of children experiencing illness (DasGupta, 2007). Yet, writing interventions with adolescents who have life-shortening diseases are feasible and acceptable (Cheng, Purcell, Dimitriou, & Grossoehme, 2015). While inaugural efforts in narrative medicine began with questions of narrativity in the clinic for healthcare professionals and medical students, the field has expanded by offering narrative medicine interventions for patients, families, and professionals (Charon et al., 2017). The outcomes of narrative medicine workshops for medical professionals may differ from the outcomes for patients; however, narrative medicine methodology remains the same. As narrative medicine continues to grow, more pediatric data are needed to determine the narrative intervention benefits, the types of stories being told, and whether these stories can inform healthcare professionals and parents of patients' values, interests, and goals of care that center on the illness experience.

This study fills a narrative research gap by determining whether stories generated through our narrative interventions in a pediatric hospital setting have the linguistic properties associated with pro-healthy outcomes. Our first aim was to examine narrative content (e.g., expressed emotion) and determine how it shapes and is shaped by the illness experience.

Historically, writing interventions have demonstrated strong relationships with health behavior (Smyth, 1998), and linguistic characteristics of emotional disclosure are associated with such health benefits (Pennebaker, 1999). A comprehensive review of studies of writing interventions with adults and their health outcomes is beyond the scope of this article; however, we highlight examples of the current state of knowledge. Bourassa and colleagues (2017) found that narrative writing in adult populations may be a durable means of improving cardiac characteristics and decreasing longer-term health risks. La Marca and colleagues (2019) demonstrated a reduction in psychological symptoms in a randomized clinical trial of an expressive writing intervention with adults diagnosed for the first time with cancer.

Writing about emotional events correlates to psychological or physical health benefits in adults; physical health benefits compared to psychological ones have generally been greater in clinical samples (Smyth, 1998; Lepore and Smyth, 2002; Frisina et al., 2004; Frattaroli, 2006). Meta-analytic studies have shown mean effect sizes ranging from very small to small/medium; the variation has been accounted for in multiple ways, including dose-response and sample types (Smyth 1998, Harris 2006, Mogk, Otte et al. 2006, Reinhold, Bürkner et al. 2018, Gerger, Werner et al. 2021).

Pennebaker described four health outcomes characteristics: positive emotions (e.g., happy, glad, joyful); negative emotions (e.g., angry, sad, wrong); words employed in causal statements (e.g., because, infer, thus); and expressions of insight (e.g., realize, understand) (1999). Narrative experience can contribute to narrative construction such that writing prompts and interventions can elicit formal

storytelling. We illustrate this with our participants' own stories and poems.

Maslej and colleagues (2020) sought to understand why expressive writing trials have sometimes shown increased negative emotional states in participants. They found that writing about negative topics was associated with increased feelings of sadness and decreased happiness; writing about a positive topic also decreased happiness, though not as much as in the negative writing group. They concluded their valence hypothesis was supported: writing about a negative topic elicits negative emotions. They found evidence cognitive processing induced by the writing topics affected sadness and happiness, suggesting valence and cognitive processing play roles in emotional outcomes in writing interventions.

For some writers, emotional writing, which focuses on reviewing negative emotions through emotional processing, can contribute to healthy coping practices. For others, a sense of mastery over a stressor may be gained by reflecting on the future with a positive attitude. Lu and Stanton (2010) suggested that reflective, cognitive reappraisal may be better for persons presenting with physical symptoms, while emotional disclosure may be better suited for those presenting with more psychological distress symptoms. Thus, investigating linguistic characteristics and how narratives are constructed by pediatric populations can be a starting point in the identification and measurement of health behaviors and outcomes.

Our study also addresses a literature gap about the value of poetry as a mode of storytelling, and how illness story categorizations are valuable. Children are learning to identify and name emotions; compared to adult populations, they are less likely to focus on their illness, but instead on aspects of hopeful living and positivity (Piko & Bak, 2006). While there is emerging literature on the value of narrative interventions, narratology, and pediatric storytelling among health humanities scholars, psychologists, and healthcare professionals, several studies focus on particular diagnoses or procedures, and gathered stories are typically prose (DasGupta, 2007; Kameny & Bearison, 1999; Bearison, 2012; Nicolopoulou, 2010; Robillard et al., 2020). In categorizing texts based on Arthur Frank's illness narrative categories as other narrative researchers have done,[1] we contribute to the relatively recent growing literature comparing adult and pediatric illness narratives and their different needs (Spillmann et al., 2017).

The purpose of our mixed-methods retrospective study was to characterize linguistic and narrative properties of texts generated by hospitalized pediatric writers who voluntarily participated in narrative medicine workshops or interventions through an expressive therapy program at a children's hospital. The primary aim was to use interpretive theoretical analysis and linguistic analysis to test the following hypotheses: (1) hospital-generated texts have linguistic characteristics consistent with texts written to improve health outcomes; (2) stories told by pediatric patients through poetry and prose can be classified using Frank's illness narrative types, situating caregivers into the pediatric writer's world in a moment in time; and (3) pediatric stories are authentic narratives that yield important insights about patients and their relationships with others despite lacking, at times, formal narrative elements (e.g., plot), techniques, and form.

Methods

Participants

This study was carried out at a 365-bed tertiary referral pediatric hospital in the Midwest. The hospital's Institutional Review Board deemed the study not to be human subjects research because the data

[1] *Arthur Frank's (1998) extensive work in narrative medicine led him to create a classification scheme of narratives into stories of chaos, restitution, and quest. Restitution narratives are stories in which everything "comes out right in the end." Chaos narratives, as the name implies, are stories of a person being acted upon, seemingly randomly, by outside forces, such as illness or trauma. Quest narratives are told by people who confront their illness or brokenness and use it as an opportunity for exploration, creation, and growth; these self-stories are about "voice finding itself" (Frank, 1998, p.133).*

were de-identified. The sample of the extant 121 texts available consisted of poetry, fiction, and nonfiction prose written by over 115 unique patients; due to the de-identified nature of the study, we believe a few patients wrote more than one text. In order to be included the document had to be typed or legibly handwritten in English. Documents that were illegible or written in languages other than English were excluded. Eighty texts (67 poetry, 10 fiction, and 3 nonfiction) were written by patients through the Expressive Therapy Center (ETC) from outpatient palliative care and/or medical/surgical inpatient floors between January 2013 and June 2019. Forty-one texts (39 poetry, 1 fiction, and 1 nonfiction) were written by patients in the Behavioral Health Partial Hospitalization Program (PHP) in group settings led by the narrative medicine coordinator (NMC; second author).

Procedures

Narratives collected from PHP were written in a group setting of approximately 5 to 11 adolescents between the ages of 12 and 18 years. The hour-long group sessions began by reading a poem, short story, or nonfiction piece, and this was followed by a guided discussion of the text. Participants were encouraged to verbalize what they noticed happening within the narrative and how they experienced the text. A writing prompt inspired by the text was provided and participants were given approximately ten minutes to write. Examples of prompts include: "write about an emotion you feel" and "describe a moment in time (past, present, or future)." Participants were free to write in any genre and not required to respond to the prompt. Though writing for, to, and often about themselves, participants were encouraged, but not required, to read their writing aloud in the group, acknowledging that peer group members and the NMC would be privy to their personal stories.

Narratives collected through the ETC were written by patients between the ages of 6 and 26 years from any hospital unit and who were referred to narrative medicine. Patients receiving palliative care were seen in the hospital through inpatient and outpatient services and at home; some of these patients also received care through PHP. After referral to the NMC, various genres and options were provided to the patient who needed further guidance on what to write. When participants wanted to write, the facilitator listened to their ideas to help them begin. If a young patient-writer wanted to write but was unsure where to begin, a traditional narrative medicine approach was utilized: the child and the NMC engaged in the reading and discussion of a text, and the NMC provided a writing prompt inspired by the text. Due to varying abilities while hospitalized, some participants requested the NMC complete the physical act of writing on their behalf; the NMC wrote exactly what was dictated by the young writer. Session duration was typically 30–60 minutes. A general discussion between the NMC and writer (and peers when applicable) after they shared their writing included drawing attention to what was noticed within the narrative (e.g., plot, descriptions, literary devices, and more). This provided the writer with the ability to feel heard and seen within their constructed narrative. The NMC did not ask or encourage other participants to ask the writer to explain the poem or story as it is important for the participant to be seen, heard, and valued within the narrative as it has been constructed. Narratives collected from both the PHP and ETC groups were numerically coded and organized based on age groups for analysis: ages 6–10 (children; n=8); 11–19 (adolescents; n=94); 20–26 (young adults; n=8).

Analysis

Quantitative analysis

Linguistic analysis was performed using the Linguistic Inquiry and Word Count (LIWC) software. LIWC provides a standardized, computer-based method for examining narratives, with a dictionary of over 2200 words and word stems; the software distinguishes over 70 linguistic characteristics, with each word or word stem having one or more characteristics assigned to it. For each recognized word in the target text, the score for that characteristic is increased by one in the LIWC program, which then reports the percentage of total words in the text for each linguistic characteristic. The psychometric properties of LIWC are well-established (Pennebaker & King, 1999; Pennebaker et al., 1997).

Exploratory and descriptive data analyses were obtained, including examination of the distribution of word percentages (e.g., mean, SD, median, range) for each of the linguistic characteristics returned by the LIWC software. Analysis was done on the whole sample and age-stratified samples. Comparison of four linguistic characteristics associated with improved health outcomes in previous (adult) written emotional disclosures was made using the Sign test (which does not assume a symmetrical distribution) to determine if there were significant differences in the present sample (Grossoehme et al., 2010). These four linguistic characteristics are positive emotion words, negative emotion words, causal emotion words, and insight words. Two-way ANOVA was used to compare the mean word percentages on those four linguistic characteristics among each of the three types of Frank's illness narratives and the sub-types of quest. All tests were two-sided, and p-values <0.05 were used to indicate statistical significance. SAS (version 9.4; SAS Institute Inc., Cary, NC, USA) was used for statistical analysis.

Qualitative analysis

Three investigators (first, second, and senior authors) analyzed the texts for themes. Analysis documented common themes arising from the texts and categorized each text using Frank's illness narrative categories (1995), quest sub-categories,[2] and combinations of sub-categories. Classification was considered feasible if consensus could be achieved by the three investigators on 90% or more of the texts. Differences in thematic coding between the investigators were resolved by consensus. NVivo 12.0 Pro was used for analysis.

Intercoder reliability was achieved with three independent coders representing different disciplines (first, second, and senior authors) examining the same data. In an iterative process, we identified words, phrases, and broad concepts from the prose and poetry, leading to naming general themes (Creswell, 2013; Rallis & Rossman, 2012). Weekly research meetings facilitated a continuous dialogue to maintain consistency and to address any substantive disagreements (which did not arise). Throughout the process, coders worked from a codebook or spreadsheet that was generated from the qualitative NVivo 12 Pro software to organize the codes and supporting texts. Any codes with fewer than four supporting texts were either not used or combined with other related codes to identify emerging themes.

Results

We present a mixed-methods analysis of illness stories generated by child and adolescent patients in diverse clinical areas in a pediatric healthcare setting.

Quantitative results

A total of 121 texts (mean (*SD*) word count: 187 (288)) were analyzed. Selected linguistic characteristics are presented in Table 1. Texts in the present sample differed significantly in three of four categories associated with improved health outcomes in adult written disclosures (Grossoehme et al., 2010). Patients' texts had lower mean percentages of words expressing insight and negative emotions and significantly higher percentages of positive emotion words (see Table 2). The pediatric texts were highly

[2] *Within the quest narrative category, there are three types including, memoirs, manifestos, and automythologies. Memoirs, or the remembrance of suffering in a person's life story, are not told chronologically, but rather "present circumstances become occasions for the recollection of past events" (Frank, 1995, p.120). For this type of quest narrative, illness "constantly interrupts the telling of the past life, although alternatively, memories of the past life interrupt the present illness" (Frank, 1995, p. 120). Manifestos, where there is a public declaration of suffering, the "truth that has been learned is prophetic, often carrying demands for social action" (Frank, 1995, p.120). It is not uncommon for memoirs and manifestos to be contained within the same stories such as in disability stories (Frank, 1995, p. 121). Finally, the automythology is the type of quest narrative where suffering is transformed into a myth through metaphors that mediate the experience of illness to others. It is metaphorically, as Frank explains, the Phoenix that "rises from the ashes of the fire of its own body" (Frank, 1995, p. 122), and describes the reinvention of the self.*

Table 1

Selected age-stratified linguistic characteristics of patient-generated texts (N=121)

	Child (n=18)		Adolescent (n=94)		Young adult (n=8)	
	M (SD)	*Median (Range)*	*M (SD)*	*Median (Range)*	*M (SD)*	*Median (Range)*
Word count	200 (256)	96 (45–897)	189 (310)	118 (27–2548)	157 9133)	136 (15–4350)
Words/sentence (n)†	39 (71)	14 (7–300)	35 (41)	16 (7–188)	81 (840	32 (12–215)
6-letter + words*	11 (5.1)	9.7 (4–22)	12 (50)	11 (2–29)	18 (9.7)	14 (7–33)
Total pronouns	15 (4.6)	15 (6–22)	18 (6)	19 (2–34)	16 (3.2)	17 (11–21)
Personal Pronouns	12 (4.8)	12 (4–20)	13 (6)	13 (0–30)	9.1 (4.8)	10 (0–15)
I	5.9 (6.3)	2.6 (0–20)	7.8 (6)	76. (0–27)	5.0 (4.5)	6.1 (0–12)
We	1.5 (3.7)	0 (0–15)	0.97 (4.7)	0 (0–15)	0.53 (1.4)	0 (0–4)
You	2 (2.4)	1.3 (0–7)	3.4 (4.7)	1 (0–18)	3.2 93.6)	2.1 (0–10)
She/He	2.2 (2.6)	1.1 (0–8)	0.90 (2.70	0 (0–13)	0.06 (0.18)	0 (0–0.5)
They	0.43 (0.67)	0 (0–1.9)	0.38 (0.93)	0 (0–8)	0.29 (0.65)	0 (0–1.8)
Impersonal pronouns†	3 (2.5)	2.9 (0–10)	4.9 (3.9)	4.6 (0–21)	7.0 (4.7)	4.9 (2.5–15)
Positive emotion	5.3 (4.4)	3.4 (0–13)	4.5 (3.4)	3.8 (0–26)	3.5 (2.9)	3.6 (0–7.3)
Negative emotion†	1.4 (1.7)	1.2 (0–6)	2.7 (2.3)	2.7 (0–10)	3.8 (4.40	2.8 (0–13)
Social	13 (8.2)	13 (0–36)	10 (6.6)	9.3 (0–27)	8.9 (5.8)	9.7 (0–18)
Family	1.2 (1.7)	0.51 (0–6)	0.41 (1.2)	0 (0–10)	0.3 (0.35)	0.23 (0–0.83)
Friend‡	1.4 (1.9)	0.69 (0–6)	0.26 (0.59)	0 (0–3)	0.75 (1.6)	0 (0–4.7)
Insight*	1.2 (1.1)	1.1 (0–3)	2.7 (2.2)	2.2 (0–11)	3.9 (1.8)	3.7 (2.0–6.7)
Cause	0.96 (1.1)	0.74 (0–4)	1.6 (1.4)	1.4 (0–8)	1.1 (1.2)	0.88 (0–3.0)
Body	1.3 (2.0)	0.68 (0–6.6)	1.5 (2.1)	0.96 (0–11)	1.2 (1.2)	0.75 (0–3.0)
Health/Illness	0.80 (1.8)	0 (0–7.7)	1.6 (1.9)	0.97 (0–9)	2.1 (1.7)	2.6 (0–4.6)
Past focus	1.8 (1.0)	0.85 (0–9.2)	3.3 94.0)	1.7 (0–18)	2.8 (3.0)	1.5 (0–7.6)
Present focus	15 (7.4)	15 (2–29)	14 (5.8)	14 (3–32)	13.0 (4.1)	13 (6.0–19.0)
Future focus	2.4 (2.9)	1.6 (0–10)	1.9 (2.3)	1.2 (0–14)	2.4 (2.8)	1.2 (0–6.7)
Space	6.8 (3.5)	5.4 (2–14)	7.0 (3.7)	6.6 (1–16)	6.4 (2.9)	6.6 (0–9.7)
Time	4.8 (3.2)	4.2 (0–14)	5.5 (3.1)	4.6 (0–15)	5.8 94.1)	5.1 (1.0–13.0)

† Between-group differences significant at P≤0.05

* Between-group differences significant at P≤0.01

‡ Between-group differences significant at P≤0.001

Table 2

Age-stratified differences of four linguistic characteristics

Linguistic Characteristic	Child Mean (SD)	Adolescent Mean (SD)	Young Adult Mean (SD)	*P*
Positive emotion words	5.3 (4.4)	4.5 (3.4)	3.5 (2.9)	0.49
Negative emotion words	1.4 (1.7)	2.7 (2.3)	3.8 (4.4)	0.042
Insight words	1.2 (1.1)	2.7 (2.2)	3.9 (1.8)	0.003
Causal words	0.96 (1.1)	1.6 (1.4)	1.1 (1.2)	0.12

present-focused and emphasized location/space and time (the here and now), biological processes (including body, health/illness, and sexuality), and were socially oriented (not necessarily family and friends, but fellow peer-patients and providers). The texts among children and adolescents used a higher percentage of positive than negative emotion words compared to young adults. Children and adolescent writers used fewer indirect pronouns. Some writers used "you" secondarily (giving advice to others), which was a method they employed to exercise authority over their body and their experiences, and/or to confront another person without actually having to do so—as evidenced by the directedness of their messages and raw emotions:

> Since the day you took a shit on my life, I've been in hospitals and nursing facilities and I haven't seen home in a year. It will be well over a year before I'm able to see my dog. Also, since your courageous day of assholery, my pet died and I wasn't able to see him before he passed away . . . But in a way, you will understand how I feel being trapped inside four walls, being told when to wake up, when to eat. But at least you can stand up and eat food without having someone feed it to you. After your sentence, you'll be able to go on with your life. (Young adult)

Several significant differences in patient-generated texts emerged when stratified by age category (see Table 1). Young adult texts had significantly more words per sentence and a greater percentage of words six letters or more long. Children's texts had a greater percentage of words about friends and family than adolescents or young adults. The percentage of impersonal pronouns, negative emotion words, insight words, and health/illness words increased in each of the three age categories.

In terms of Frank's categories, the 18 children writers provided more quest narratives (n=15) than other types (chaos (n=0); restitution (n=3)). The adolescent group (n=94) produced significantly more quest narratives (n=69) but also wrote the largest number of chaos narratives among all three age groups ((n=19); restitution (n=6)). Finally, the young adult group (n=8) provided a sampling of each of Frank's categories (chaos (n=4); restitution (n=2); quest (n=2); p=.006).

Qualitative results

Qualitative analysis was done independently by the same three coders, and differences in coding were resolved by consensus. Analysis revealed three general themes: *Existential*, *Relationships*, and *Self*. Within these themes, the texts were classified into 10 categories and 23 sub-categories (see Table 3). In addition, stories were analyzed for their technical elements, including the literary tools that were used in writing and the types of narratives that captured the illness experiences. The following section details findings based on the thematic categories and sub-categories.

Existential theme

We used the term "existential" to mean "concerned with human existence and meaning of life." As

Table 3

Codes, categories, and emerging themes

Theme	Category	Subcategory	Exemplary quotation
Existential	Spirituality		
		Afterlife	Sometimes I'll lift up the stuffed animal / with the necklace around its neck and smile at the beads / knowing he's with me always, that I'm never alone. (Adolescent)
		Angels	There's a certain kind of someone, / Floating through the air, / Although I cannot see her, / I can't help but to stare. (Adolescent)
		Demons	angel of darkness, / confide in me, / for I show no light (Adolescent)
		Spiritual Values	The bright blossom of peace blooming when you are / exactly where you're meant to be/ (Young Adult)
		Prayer	When I have no hope, I pray / I pray everything will be okay (Young Adult)
		Soul	My soul wants to walk away from the chair / And live a non-medical life / Because I basically live in a hospital / And I'm tired of it. (Adolescent)
		God	The voice said everything / would be OK he was there with / her no matter what. That / voice was god. (Adolescent)
	Journey		I've been sad and happy / Been strong through tough times / I've shouted and been crabby / I've walked through landmines (Adolescent)
	Mindfulness		Sit and drink warm tea / like it was a bright new day. (Adolescent)
Relationship	Nonfiction	Family	Oh water can you give me more energy? / I would like to play and have a race with my sister. (Child)
		Friends	Exhale all the sharp anger / pent up inside and leave room / for new blossoming friendships (Adolescent)
		Healthcare Professionals	I will remember you bright like the sun / Such helpful people in many ways / I wish you all happiness in every way. (Adolescent)
	Fiction	Superheroes	Spiderman gave me his webs / so I could squirt people / and be a superhero all by myself / (Child)
		Villains	Today, they're meeting to make a plan to save the planet from an evil villain that is trying to hurt kids with CP. (Child)
Self	Control and Survival		The time will come when you will have to choose / Spinraza or without Spinraza, / a drug that helps you or drives pain to you. / Remember you can decide to take it or not, / that you can try to do things yourself. (Adolescent)
	Identity		I'm trans- / parent. // It feels like I'm a woman trapped / in a man's body. / The image in the mirror / doesn't match who I am. // The reflection of the girl I want to be / is trapped in a body / where it doesn't belong. (Adolescent)

Table 3 ***(continued)***

Codes, categories, and emerging themes

Theme	Category	Subcategory	Exemplary quotation
	Values	Acceptance	Give yourself some time / to endure what life has to bring: the loud / strike of lightning, the pounding / rumble of thunder. Wait for the storm / to calm, for the bright sun to crack through the clouds. (Adolescent)
		Altruism	The hidden heart . . . Constantly working without thoughts for itself, / it selflessly beats day and night. (Adolescent)
		Care	The doctors tell my mom bad news / There's no antidote and I might not make it through / I see the worry in her face / could this really be my last time and place / They took me in and took my rights / I stayed in the psych ward for 5 nights / I was scared at first but got some help I needed / they treated me with kindness they really cared / the other patients made me feel welcome there/(Adolescent)
		Fairness	If people in our life make / you feel any other way you need / to get rid of [them] because it's / not fair to you. You deserve to / be happy. (Adolescent)
		Peace	I hear the whispers of the past. / I want to find peace. / I am lost and found. (Adolescent)
		Trust / Honesty	I'm from the place where feeling invisible / is normal. / I'm from the place of disrespect. / From the place of being misunderstood. / From the place of no trust. (Adolescent)
	Ill-health	Disability	My anatomy, an exception to normality, / is flawed but still defeats all odds. / It flies beyond the hospital walls / in search of more and more healing. (Adolescent)
		Mental Illness	I thought I had anxiety / but it's the other way around / anxiety has me / it has me all pinned down (Adolescent)
		Suicide	I just felt like a disgrace / I just wanted to leave this earth without a trace // But then I met you and my life began to change / I found my life not so troublesome or so strange (Adolescent)
		Trauma	I was rape[d] as a young girl and I kept my mouth quiet so I wouldn't make the news, people through my past in my face like I just didn't have feelings never thought my reputation would end up like that. (Adolescent)
		Disease or Disorder	Cystic Fibrosis is mucus that is really, really thick, and it builds walls inside my lungs and makes it hard to breath. Imagine the Great Wall of China inside your lungs, now try to breathe. (Adolescent)
	Death		The day she told me it was going / to get better soon. And the day she / left my world forever, leaving me / all alone in a world I didn't want / to face on my own. (Adolescent)

a broad theme, existential embodies spirituality, the philosophy and practice of mindfulness, and the concept of the life journey—all of which were captured by both pediatric groups. Several young writers referred to angels, karma, the act of prayer, God, faith, and other spiritual references. Thus, the category that emerged within the Existential theme, Spirituality, including the few references to religion or non-secular beliefs, was used to organize 7 relevant sub-categories: Afterlife, Angels, Demons, Spiritual Feelings and Values (Hope, Faith, Love), Prayer, Soul, and God. For example, one adolescent writer wrote, "Suppose animals listen to the prayers of people that spill out of their souls." Another writer expressed, "A friend could be a dog or a puppy / Or it could be God" (Adolescent). The category of Journey captured how our subject population attributed meaning in their lives and within their illness journeys. It was not uncommon for pediatric writers to present a fictional story or poem, quite possibly to mask the reality of what they truly felt: "And Mr. Crude is shouting, 'You can't walk- you're never going to walk!' // But D-Dude isn't going to have any of that. / He uses his encouraging powers / to take their discouraging powers away" (Child).

A third category, Mindfulness, captured patients' experiences of self-consciousness or self-awareness and their inquiry into their own human existence. The young writers explored what it means to be present or to exist through a closer self-examination of their thoughts and bodily sensations. For example, one adolescent wrote, "Live so you can taste the ice cream as it / melts on your tongue and fills your mouth / with a cold, flavorful sensation / . . . Live so you can live instead of survive." The Existential theme identifies those narratives or stories that illustrate how pediatric patients grapple with the meaning of life and seek out explanations, external support (e.g., angels and God), and ways to cope beyond what they experience in the clinical setting or within their relationships.

Relationships theme

We found a significant overlap with the Existential theme and our second theme of Relationships, whereby fictional and nonfictional characters and relationships similarly attempt to explain the meaning of life, of human behavior, and the purpose of the illness journey. We identified fictional relationships, including the two subcategories of superheroes and villains, as well as nonfiction relationships, with three additional subcategories of healthcare professionals, family, and friends; this category includes those who have passed away (e.g., siblings or friends) but who continue to give hope to an ill child. For example, in a poem titled "Heavenly Necklace," an adolescent writer wrote, "Sometimes I'll lift up the stuffed animal / with the necklace around its neck and smile at the beads / knowing he's with me always, that I'm never alone. / Knowing the beads are close together / reminds me he brought family and friends closer together. / And seeing the colors of the rainbow tells me he [stepbrother] is in peace."

Self theme

The third theme, Self, was expectedly prominent in the collection of texts as this was an opportunity for pediatric writers to express and expose their feelings, values, and experiences of illness. A total of 5 categories emerged from the qualitative analysis, including: Control and Survival, Identity, Values, Ill-Health, and Death. Patients expressed optimism and courage as they took control over their illness or focused on their own survival. The metaphorical battle or fight to control pain or cancer or depression was used among young subjects in both the PHP and medical/surgery programs. One young writer wrote, "Going upstream is never easy. But my pain has given me the strength to fight. And I hope you will fight with me" (PHP Adolescent). A medical/surgery adolescent captured the persistence to survive in a lyrical poem: "You still have your dreams to go for, and the heart to fight that black cancer if it's back."

There were no discernable differences between the two groups of writers under the category of Identity; patients who wrote about identity emphasized the importance of being true to themselves and the desire to be better understood by others. For instance, a PHP adolescent implored the reader not to judge them based on appearances: "What you see when you see me / is to your surprise, a lie. / I am

someone other. / You take one look, / you judge the book / only by its cover."

In the third category, Values, a total of 6 subcategories emerged from our analysis, including Acceptance, Altruism, Care, Justice (Fairness), Peace, and Trust/Honesty. These are in addition to the spiritual-based values of Hope, Love, and Faith, which emerged within the Existential theme and were often connected with God or patients' spirituality. Pediatric writers identified values in one or more of the following ways: 1) their desire to secure values such as seeking justice (e.g., Fairness); 2) descriptions of how their values have been ignored or violated (e.g., Trust); or 3) explanations about how their values have helped them in their illness journey (e.g., Acceptance). Multiple values were expressed in this excerpt from an ETC adolescent writer: "I will travel to the city of Rise / where the streets are sleek, / the people are beautiful, / the sky is purple and cloudy, / and buildings are complex but hold elegance. // There I will find trust like weight off the shoulders, / acceptance as calm as the leaves of a tree ruffling / and hope like the sun rising." This excerpt further elucidates the overlapping nature of identified themes, categories, and sub-categories.

Ill-health, the fourth category, yielded 5 subcategories including Disability, Mental Illness, Suicide, Trauma, and Disease/Disorder. The stories of illness, hospitalization, and treatment, and the impact of traumatic events and behaviors were captured during, or soon after, an event. For example, a young adult patient described current thoughts during hospitalization: "There are nights that I wake up crying over everything that's happened. And sometimes, I wish my life would end. Most people say, 'You need to be happy that you're alive, that you survived' but really—I'm alive and trapped in a hospital bed." Some of the texts illustrated how patients reflect on past experiences and capture their self-awareness. "Thoughts repeat and the pain gets worse / The blade goes deeper / It doesn't hurt / Seeing the blood drip from my veins / I enjoy the sight / even though it's not sane" (PHP Adolescent). Several of our young writers revealed how they think about or make sense of their illnesses through poetry. For example, an adolescent medical/surgery patient described the word "cancer" in a lyrical poem: "Cancer / It's a letter away from cancel / probably because it likes to do that / Can-her, can-cer, can-cel."

The final category, Death, was rarely written about by our pediatric population (Table 1: M(SD) =0.19% (0.14%)). The few who referred to death were reflecting on their mortality after surviving a suicide attempt or trauma, or looked at death as the separation of body, mind and/or soul: "Sometimes I worry the end is in sight / My body's alive, but my soul is dead / We walked hand in hand as our love took flight / Do you ever think of me late at night?" (PHP Adolescent). Death was also referenced by young writers who had lost a loved one.

The majority of patients wrote about hope, survival, past pleasurable experiences, or future-oriented events. Superheroes, sports, video games, and those objects and leisure activities that often give children pleasure were common subjects despite their current hospitalizations and illnesses (See Table 1 "Leisure": M(SD)=1.41% (2.31%)).

Style and illness-narrative types

Genre and literary devices

Our analysis identified several technical elements, including genre, literary tools (imagery, metaphor, personification, repetition, and rhyme), and the use of titles and their content. Increased expression of negative emotions correlated with increased use of impersonal pronouns (Pearson's r =0.19; p=0.033). No significant relationship existed between the other pronouns (I, you, she/her/he/him, we, they) and negative emotion words.

Findings showed that 106 (87.6%) of the texts were written in the form of poetry while 11 (9%) were fiction, and only 4 (3%) were nonfiction. It is important to note that texts by participants were written after reading and discussing a poem or story and thus their writing may have been cued from the form of the text discussed. Due to texts being de-identified, data regarding the connection between texts presented and texts written is not available. In subsequent sections, we describe how the hospital setting might consciously or subconsciously impact

or influence our young writers, illustrating the importance of place in lived experience of illness, hospitalization, and new care-based relationships. Although a small minority of texts were classified as nonfiction, many of the poems and stories explored personal experiences and content through fiction. For example, a child wrote a fictional story about children with cerebral palsy (CP) who worked together to stop a bully: "While Zoe is taping up Zach, the other kids call the cops and say, 'This bad person is trying to hurt kids with CP. Can you please come and we'll put him in the back of your truck.' Once he's with the cops, they all say, 'Bye bye' and then go back to the special house and stay the night. The Helping Club saved the lives of all kids with CP." Another example was provided by an adolescent poet who metaphorically described their experience:

> The time will come when you will have to choose / Spinraza or without spinraza / a drug that helps you or drives pain to you. / Remember you can decide to take it or not, / that you can try to do things yourself. / Remember how the caterpillar stays in its cocoon / before its wings stretch open. It doesn't need help. It does this on its own.

These findings suggest that children and adolescents are using fiction and poetry to explore and express their real-life (i.e., nonfiction) experiences and emotions.

While many different literary devices were utilized by the young writers, 85 (70%) of writings contained imagery, 69 (57%) contained metaphor, 17 (14%) contained personification, 36 (29.7%) contained repetition, and 25 (20.6%) utilized a rhyme scheme. All texts, including nonfiction, utilized at least one literary device. In one such example, after providing the scientific definition of cystic fibrosis, an adolescent patient described, "Now that is the sciency definition. My definition: Cystic Fibrosis is mucus that is really, really thick, and it builds walls inside of my lungs and makes it hard to breathe. Imagine the Great Wall of China inside of your lungs, now try to breathe." Close examination of the literary devices being used by pediatric writers provides insight into how children and adolescents integrate creativity into their narratives.

An analysis of titles revealed significant themes that involved objects, emotions, experiences, and persons/groups (see Table 4). It is worth highlighting that 28.9% of poems and prose were untitled.

Types of "illness" narratives

After a close reading of each text, we independently categorized the writings into one of Frank's illness narrative types and arrived at a consensus: 19% were identified as chaos narratives; 8% restitution; and 73% quest. Of the quest narratives, 8% were memoirs, 19% were manifestos, 35% were automythologies, and 11% were a combination of 2 types of quest narratives. In writing about their transformative journeys, pediatric writers did not always explicitly describe their illness, but instead described their experiences of being cared for, their future-oriented goals, including but not limited to health-based goals, and their aspirational identity formation (i.e., who they want to be). Here is one example about a transformative journey that does not explicitly describe an illness.

> Story of My Path
>
> The path I have walked has been difficult
> full of ups and downs
> and turnarounds
>
> I've wanted beaches with calm waves
> but I've been through cracks in the maze
>
> The sky has been terrifying
> and it has also been full of sunshine.
>
> Every tree has held my difficulties
> Every leaf has held my happiness
> Every mountain was hard but I've succeeded
>
> The paths I didn't take are past me
>
> Wherever I have stumbled
> I've found my confidence to keep walking
>
> I've waited for better results
> and received a gold star
>
> The path I walk now is sometimes bumpy
> but I'm still smiling, still giggling,
> still wanting *YOU* to know
> there's hope inside of *YOUR* soul
>
> —Adolescent

Table 4

Literary tools table

Category	Subcategory	Total N (%)	Exemplary quotation
Genre	Poetry	106 (87.6)	Breathe out perforated pain / because it's getting too heavy // Exhale sore sickness / and inhale the deep blue hues / of calmness (Adolescent)
	Fiction	11 (9)	And like magic, without cracking the egg, a red dragon flies out and wraps himself around his amethyst birthstone. He looks around and sees there's no one in sight. (Adolescent)
	Nonfiction	4 (3)	I came to the hospital originally because . . . I don't even remember. Wait, I do. The ulcer. I had a wound on my butt. On. My. Butt. . . . I had to stay on one side or the other for months. I had to look at everything from a sideways perspective. (Young Adult)
Literary Tools	Imagery	85 (70)	I walk towards it and find myself coming upon a creek, flowing so slow and peaceful, surrounded by trees getting ready for their long winters nap. Their leaves are orange red yellow and brown. One starts falling but stops midway in the air, then I realize that this isn't a dream but yet a moment in life. I feel myself wanting to see and feel what happens next in life. (Adolescent)
	Metaphor	69 (57)	I am a cloud waiting for the perfect / person to rain my thoughts on. (Adolescent)
	Personification	17 (14)	"Letter to Loneliness" I try to seem friendly, but no one comes near, / your embrace is frozen, but you hold me dear. (Adolescent)
	Repetition	36 (29.7)	What if the sun could yell out the time like a clock? / What if dogs could tiptoe across the snow and bring me hope? What if my boots kicked sorrow like a soccer ball? What if my sweatshirt wrapped me in laughter? (Adolescent)
	Rhyme	25 (20.6)	Hope is a flower that blooms in spring. / It brings joy and beauty to everybody. / Hope is the spirit that the birds chirp and sing. / Their song is such a perfect melody. (Child)
Titles (85 titled; 35 untitled)	Objects	20 (16.5)	The Dream Locker (Adolescent); Things that Have No Name (Adult
	Emotions	11 (9)	My Happy Place (Adolescent); What is Hope? (Child)
	Person/group	11 (9)	I Will Always Be (Adolescent); The Helping Club (Child)
	Experience	25 (20)	My Train Ride (Adolescent); To the sixteen shots of crown that destroyed my life (Adult)
	Untitled	35 (28.9)	
	Other subject matter	18 (14.8)	The Hidden Heart (Adolescent); As Sparkly as My Heart (Child)

Table 5

Differences in mean linguistic characteristics between narrative categories (ANOVA)

Linguistic Characteristic	Narrative Category, M(SD)						F	*P*
	Chaos	*Restitution*	*Quest*					
			Memoir	*Manifesto*	*Automythology*	*Combined Quest Styles*		
Cause	1.7 (1.7)	2.0 (0.98)	0.92 (1.2)	1.8 (1.9)	1.3 (1.2)	1.4 (0.92)	1.12	0.35
Insight	2.7 (2.5)	2.6 (1.4)	3.1 (3.0)	2.3 (1.9)	2.5 (2.1)	2.3 (1.6)	021	0.96
Negative emotions	3.8 (3.2)	3.2 (1.5)	3.4 (2.3)	1.2 (1.5)	2.0 (2.2)	3.4 (2.2)	4.49	0.001
Positive emotions	3.4 (2.8)	2.4 (0.7)	6.4 (2.2)	4.8 (3.2)	5.5 (4.5)	3.7 (2.8)	2.65	0.026

Analysis of variance (ANOVA) showed significant differences between narrative categories for the frequency of positive and negative emotion words (see Table 5). Memoirs had the most positive emotion words (F=2.65, p=0.026; M=6.4; SD=2.2) and restitution narratives had the fewest positive emotion words (M=2.4; SD=0.7). Chaos narratives had more negative emotion words (F=2.49; p=0.001) than other categories (M=3.8; SD=3.2), while manifestos had the fewest (M=1.2; SD=1.5). There were no significant differences among categories for the use of causality and insight words.

Pediatric writers' journeys of illness

Our pediatric population emphasized their journeys of illness, recovery, post-hospitalization goals, and, importantly, their self-awareness of being *on a journey* and what they are feeling or experiencing in a given moment of time. For example, one adolescent patient wrote a self-personified story about an umbrella and a family in need:

> My meaningless journey began in a small café on the corner of a busy street. . . . I was still lost and confused. Am I a weapon? Am I a cane? It seems everything has a purpose but me . . . And here I float, uselessly, and without purpose, confused and miserable. What am I? . . . A young boy, with only a few rags for clothing, picked me up by my handle. . . . The boy carried me over to his parents. "Here mama, here papa, this umbrella will keep us from getting wet, even though it has a tear in it. . . . The family huddled under me, grateful of my purpose.

Through the personification of an umbrella, our patient tells the reader that they can be appreciated and have purpose, regardless of possessing an imperfection (i.e., a tear). Although the word "journey" was explicitly used in this text, the majority of pediatric narratives—both implicitly and explicitly—described a journey or process toward change.

Hence, Frank's category of quest narrative was prominent, particularly among the child and adolescent populations. Through our linguistic analysis and coded data, we found less description about patients' past lives, other than the relationships they have fostered (healthcare professionals, family, and friends), and a greater inclination to write about what they are feeling or experiencing in the current moment and how they perceive their future selves and goals. In one such example, an adolescent patient writes:

Journey of Breath

Breathe out perforated pain
because it's getting too heavy

Exhale sore sickness
and inhale the deep blue hues
of calmness

Breathe out the soft suffering
and breathe in the moon
so it can reflect peace

Exhale all the sharp anger
pent up inside and leave room
for new blossoming friendships

—Adolescent

Through their quest-like stories, a clear transformative experience can be identified, along with an almost prescriptive account to guide future patients (i.e., lessons learned to help the next patient), or a confirmation to the reader that healing has started. The latter accounts fell into the quest sub-category of manifestos (often included memoirs at the start of the text, but then transitioned into manifestos). Below is an example of a poem by an adolescent that begins writing memoir and then transitions into manifesto; thus, it was ultimately categorized as a combined quest style (see Table 5):

Landmines

I've been sad and happy
Been strong through tough times
I've shouted and been crabby
I've walked through landmines

When I couldn't play with friends
I felt all lonely and bored
When I had no control to bend
I wanted to leave and slam the door

I found my strength in music
Grabbed confidence in friends
Strummed my heart with a flick of my pic
Designed cool swag and started a trend

So when you're sad and happy
Be strong through tough times
It's okay to shout and be crabby
Walk through those landmines

—Adolescent

Others, particularly the children and adolescent groups, illustrated their courage and resilience not through a traditional illness narrative, but by the imagery and metaphors that relay to readers that they are surviving. One adolescent provides an example through a poem titled "Pain" and writes, "It feels / like a knife crossing your heart. It sounds like anger, and agony / but is also misery . . . However in my / case I choose to set it free. As / sad as you may be never lose faith / you'll always have me." A significant number of texts used imagery (70%) and metaphors (57%) to express thoughts and emotions and describe relationships (see Table 4). We attribute the use of imagery and metaphors to the process of the narrative intervention wherein patients were first exposed to a variety of poems, short stories, and other writings, often with the opportunity to discuss their interpretations and feelings, and then tried to imitate the writings, or creatively construct and write their narratives without following a provided prompt or example. Other factors that could lead to the shape, structure, and content of the pediatric narratives could be related to the hospital/clinical setting where the workshops and sessions took place. For example, some of the young writers included superheroes in their stories and poetry which is a hope-based public relations theme at the hospital.

We further found that through their imaginative elements and demonstrated kinship with caregivers, the texts were hopeful, playful, and charismatic. These stories presented quest-like insights; as such, they can be valuable for healthcare professionals, parents, and others in caring for these children through optimism and play, while simultaneously reminding us that our populations are well aware of their clinical reality (e.g., "Imagine the Great wall of China inside your lungs, now try to breathe"). Many of our adolescent and young adult populations, who are more in-tune with their illnesses, described the (often) long road ahead toward recovery (e.g., "It will be well over a year before I'm able to see my dog . . . at least you can stand up and eat food without having someone feed it to you"). For many of these patients, illness and their experiences are not chaotic or negative (as evidenced by the few chaos narratives (19%) and minimally expressed negative emotions compared to positive emotions), and they

are insightful in their understanding of themselves in relation to others as evidenced by the descriptions of their relationships and the meaning of those relationships (see Table 3 for examples and Table 1 regarding insight words). Compared to adult populations, our pediatric population expressed more positive emotions (see Table 1) despite the paucity of restitution narratives where we would expect to find a locus of positive emotions (related to being "healed," "cured," "fixed"). The lack of restitution narratives (8%) may be attributed to the writing interventions occurring while many of our patients were hospitalized rather than post-hospitalization. Nonetheless, regardless of age or program, our population was hopeful and viewed their situations as transformative; they did not expect to be the same as they were before hospitalization (e.g., "With markers I can outline the blueprints of life and build it with my own hands"). One could further extrapolate from our findings that this population received messages from their healthcare providers, families, and/or communities that there is hope, love, and support—that healing is a journey, and it is important to focus on what matters most: social relationships, imagination and play, prayer, and self-awareness. The rhetoric of heroism in healing comes through the stories of heroes and villains, of control and survivability, and of guiding others through poetic messages. An example of this can be found throughout the poem "D-Dude."

> D-Dude's Story
>
> D-Dude, with his mohawk and orange mask,
> green outfit and blue cape,
> has a hero's voice.
>
> Do you know his face can't be revealed
> to the villains, or they'll catch him
> and find where he lives.
> D-dude uses the command remote to drive
> his dude mobile to the villains.
> X-Dude is trying to shrink D-Dude's muscles.
> Mr. Smooth is making the ground slippery, so
> he falls.
> And Mr. Crude is shouting,
> "You can't walk, you're never going to walk!"
>
> But D-Dude isn't going to have any of that.
> He uses his encouraging powers
> to take their discouraging powers away.
>
> And that's when they turn into regular kids,
> Jimmy, John, and Joan.
>
> And that's when we learn to never be mean
> or you'll turn into a villain.
>
> Now with his superiest-super-mega-power,
> encouragement, D-Dude is ready to walk
> just like his friend who made him.
>
> —Child

We also found that many pediatric writers emphasized location, space, time, their communities, and paying close attention to their surroundings within the hospital and those future settings they could imagine themselves within. For example, an adolescent wrote a poem that explores the "heart" of the hospital: "It beats for children, / aches for emptiness / and hopes for healing. // It breathes for the day / when it will not be needed. . . . Constantly working without thoughts for itself, it selflessly beats day and night. This hidden heart has stolen mine." Generally speaking, the PHP and medical/surgery cohorts were in the moment and/or future-oriented, which could be valuable to the healthcare professional who is trying to understand a patient's lived experience, particularly one who is less verbal and has not yet formulated trusting relationships with the medical team. The overall benefit of this study, then, is to illustrate the need to provide alternative tools for providers to meet their patients in the midst of their illness, to tune into certain features of their patients' stories, and to become part of the patient's journey within their stories.

Discussion

From the data analysis, there are three essential organizational categories to describe our interpretations. The first focuses on the value of story-telling and narrative construction for pediatric patients and the significant number of quest-like poems, which provides further insight into their journeys. The second emphasizes the "so what?" inquiry into our research; here we delve into the importance of narrative elements and why caregivers ought to closely read and inquire about their pediatric patients' stories to enhance the therapeutic relationship and

see patients as more than their diseases or their assumed sick roles. The third category emphasizes the concept of narrative humility and how illness stories in the pediatric world do not assume rigid structures or deliberately and overtly call out experiences of illness given that this population cannot always articulate their experiences comparable to adults (DasGupta 2007); these stories can sometimes conceal the difficulties of illness or reveal more positive perspectives of illness and hospitalization.

The role of narrative in interactions between provider and patient can be best described as "emplotment"(Brooks 1992), or specifically "therapeutic emplotment" (Del Vecchio Good et al., 1994; Mattingly, 1994; Mattingly, 1998), where providers do not merely prescribe treatments and restore patients, but "co-construct with the patient a new plotline of perseverance, optimism, and healing, replacing him at the center of an integrated, coherent, and dynamic story" (Meldrum, Tsao, and Zeltzer, 2009). Therapeutic emplotment is a way for providers to make sense of illness by essentially making sense of a patient's story. Del Vecchio Good et al. (1994) defined "therapeutic emplotment" as an "interpretive activity, present in clinical encounters, through which clinicians and patients create and negotiate a plot structure within clinical time, one which places therapeutic actions within a larger therapeutic story" (p. 855). However, what often gets ignored in this interpretive activity is the "unspoken narrative," or the patient's story that speaks of cynicism, fear, anxiety, and so forth, and not the co-constructed story of illness, treatment, hope, and survival (Crossley, 2003). Thus, it is essential for providers to pay close attention to their own stories—constructed or co-constructed with patients—that speak through the silence, or the narrative that has not yet been told or written. To have a pediatric patient work with a narrative medicine facilitator and write or orate their innermost thoughts, feelings, and imaginings is a step toward revealing the "unspoken narrative."

Through the activity of writing their stories, patients find a safe space to reflect and examine their own situations, innermost feelings and attitudes, and relationships (Mattingly, 1994; Mattingly, 1998). Further, when these stories are shared and entrusted with caregivers, not only could essential social and clinical information emerge, but we suspect also a deep therapeutic bond can develop, endure, and ultimately improve health outcomes. This bond is not simply that which emerges from co-constructed narratives, but from attending to the silences and valuing the once-unspoken narrative that a child writes for themselves, but may share with their provider, parent, or other. The sharing of the once silent or unspoken narrative is an act of trust in the deepest sense and can reveal the truth of the illness experience.

Due to de-identifying pediatric patients' stories and our encounters with them for this study, we must interpret their relationships with others and us as readers through the linguistic properties and content contained within the stories. Some of our young writers employed both first and third person, likely attempting to distance themselves from their family and doctors, while having the space to individuate themselves and be heard. How our patients perceive us as healthcare professionals through the stories they tell can provide a wealth of knowledge about who we are as persons, the virtues (or biases) we bring to the therapeutic encounter, and the healing that occurs by listening, reading, and sharing their stories. Such a therapeutic encounter can enhance clinical history taking, transforming this practice into "clinical history sharing." In the narrowest sense, "taking a medical history" involves collecting patient data in the effort to gain an accurate diagnosis. By listening to and reading patients' shared stories, healthcare professionals do not "take" data. Rather, information is *given* by the patient. Clinical history *giving*, then, promotes whole-person care and establishes a genuine therapeutic relationship that empowers the often socially voiceless pediatric patient.

Family caregivers gain more insight into their loved ones' illness experiences, hopes, and future goals, including how the child sees family caregivers and others as characters within their stories. Too often a parent's perception of their child's illness experience does not always align with what the child is genuinely feeling or thinking, as we are

reminded that illness narratives differ based on whether the narrative is being told by the affected individual or by a parent on behalf of their child (Spillman et al., 2017). Many of our young writers tell us—parents, siblings, doctors, and others—to listen and to acknowledge they are scared. Instead of telling the patient "everything will be okay," or identifying them as a "hero," "fighter," or any number of characterizations that promote hope and make *us* feel better, this patient wants to reveal the truth that they are not okay.

Thus, these texts can be tools to help parents and other caregivers better understand their own child's experiences. Specifically, as Piko and Bak (2006) explain (p.644), "Information on children's knowledge may help health professionals develop age-appropriate explanations of illness and preventive health programs . . . [and] is particularly important in terms of understanding causal processes in childhood" (p.644). Furthermore, as our conclusions confirm, Piko and Bak (2006) describe that younger children have more positive health attitudes than older children.

It is important to note that Arthur Frank (1998) offers his illness narrative classification schema with two cautions: these are descriptive categories, not diagnostic; and they invite the storyteller and listener into a relationship in which narratives are given and heard as gifts, without judgment. Analyzing written narrative disclosures in this way may lead to a change of clinical approach by a provider to better engage the writer in their healing. It is important to recognize that, while pediatric narratives can aid in diagnosis, they are not meant to be diagnostic due to a variety of factors such as misinterpretation of metaphorical narrative content. Our pediatric populations' narratives fall into each of the Frank categories, which guides our analysis of how this population either directly or indirectly expresses their illness experiences, along with the understanding that some of their narratives lack those elements (e.g., plot) or structure that we would find among adult narratives. In some cases, the texts we analyzed were simply the raw materials (i.e., a story) of a narrative, but could be loosely classified using Frank's categories, nonetheless.

Narrative elements and therapeutic relationship

The themes that emerged from an extensive examination of each text, including Existential, Relationship, and Self, gave us insight into what pediatric writers focused on in their storytelling, including the subjects and objects that truly mattered and why. Despite being in the hospital for a range of mental and physical illnesses, their optimism, hopefulness, sense of feeling cared for, and being part of a community were prominent in their stories. This is even more remarkable when we consider that for some of these patients, this might have been the first time they had been cared for by another, and for some of these patients, their illness cost them their lives. While there were texts that spoke to disability, illness, and death, these were few in number, and the writer rarely expressed negative emotions even when deliberately telling a genuine illness narrative. Instead, pediatric writers emphasized positive feelings, transforming themselves into superheroes fighting evil villains, or transporting themselves to places they enjoy. By reading and listening to these stories, healthcare professionals can shape their behaviors and care for their patients while also allowing the patient to feel authentically heard. Again, by providing children with the space to create/co-create their own history, we move from "taking a history" into "history giving," allowing the patient and family to play a central role in giving their history rather than providers taking it. Patients and families have the opportunity to give the history that really matters to them, and healthcare providers receive the child's history and build trust within the therapeutic relationship. As Sisk and Baker (2019) explain, the expression—and reception—of a patient's narrative to their healthcare provider is a key means of developing trust in the patient-provider relationship and clear, effective communication. When a child / young adult's aspirations, values, likes and dislikes are seen, this can empower them to feel like the hero, the teacher, the problem-solver and so forth. What emerges are the roles pediatric writers can assume and be recognized for; they are telling us very clearly their illness does not define them.

Steeves and Kahn (1987) note that persons are better equipped to face suffering when it has meaning, and that meaning is often generated through experiencing a serious event without being overcome. Coping that involves actually constructing meaning leads to better adjustment to serious experiences (Park, 2010). One form of coping involves the crafting of a narrative; meaning is constructed as a response to the experience and can positively influence health outcomes such as decreased pain and medication use and improved mental health (Pennebaker, 2000; Park et al., 2008; Wong & Ussher, 2008). Constructed meaning may play a direct or indirect role in outcomes, such as psychological wellbeing (Park, 2010). In a study of adolescents with cancer, Grossoehme and colleagues (2020) found that spiritual beliefs were related to patient-reported outcome variables such as anxiety, depression, and fatigue, through their sense of meaning.

In examining the linguistic properties of these stories, there is a significant use of impersonal pronouns. Rather than identify the "other" in many cases (be it a person or the illness itself), stories reveal an abundance of impersonal pronouns, such as "someone," "no one," "everyone," and "something," which are used to conceal the identity of the subject or object. The use of impersonal pronouns is also very closely tied to subjects that expressed negative emotions, despite the overwhelming number of texts that were more positive. This finding is very important for caregivers as the use of impersonal pronouns and the relationship to expressed negative emotions is likely symbolic of avoidance behavior, i.e., not wanting to confront the illness, the bully or villain, or some other object or subject that is negative in some particular way. By directing attention to the patient's use of impersonal pronouns, a caregiver can enter a conversation and ask the child about the use of these words and relevant metaphors (e.g., "who is this 'someone' you are talking about in your poem?"), or talk more directly about the emotions. It is essential not only for children and young adults to tell their stories, orally or in written form, but also for healthcare professionals to examine them, closely listening to what is being said and being more attentive to the use of certain words. Even the use or absence of titles can be an important indicator of how a storyteller is expressing themselves. Not titling a poem can force the reader into a more immediate experience of the poem; the reader becomes "engaged" with the absent writer rather than simply the written, often polished, edited, and titled product. Examining how and why stories are being constructed and told can help uncover the meaning and representation of patients' illnesses.

However, it is also essential that healthcare professionals are trained through narrative workshops and mentoring so that they increase their narrative competence, recognize avenues that lead to affiliation with patients, and do not misinterpret their patient's stories. Misinterpretations can lead to ineffectual, if not harmful, therapeutic interactions. For example, a healthcare professional might think the patient is sharing a restitution narrative and assume the patient's emotional or physical healing is complete or resolved, when in fact, the patient is sharing a quest narrative. By misinterpreting what a patient is conveying through storytelling, healthcare professionals might miss an opportunity to recognize a patient's transformation and growth or to provide those needed resources and opportunities that are essential for the patient's journey. Through narrative medicine workshops, conferences, and other opportunities, healthcare professionals can develop close reading skills, which help with the identification of essential narrative components such as plot and narrative themes (including the various themes we have identified in this study).

Narrative humility in pediatric narratives and interventions

Through this mixed methods study, this research team anticipated potential criticism about the process and outcomes of our narrative interventions in the clinical setting, and the high value we place on the poetry and prose written by our pediatric writers. Our narrative program continues to be evaluated by patients and families, as well as our health teams, as to whether writing interventions improve patients' health. The first step in our research program was to analyze the texts written

by 121 patients, who were inspired by our NMC or the writing prompts provided by our NMC. Our initial observations were that these texts were not like what we have experienced in adult populations, particularly the number of poems that were written by the pediatric writers and the level of positivity and hopefulness. These texts range in sophistication and complexity (likely due to age and state of illness), challenge our expectations of what pediatric patients are thinking and feeling, and are ambiguous with metaphor and imagery. Yet, what our patient's narratives (and raw stories) teach us is narrative humility. DasGupta (2008) writes:

> Narrative humility acknowledges that our patients' stories are not objects that we can comprehend or master, but rather dynamic entities that we can approach and engage with, while simultaneously remaining open to their ambiguity and contradiction, and engaging in constant self-evaluation and self-critique about issues such as our own role in the story, our expectations of the story, our responsibilities to the story, and our identifications with the story—how the story attracts or repels us because it reminds us of any number of personal stories. (p. 981)

The need to have an accurate, well-structured narrative that speaks directly to the illness experience of the patient (or observing caregiver) is driven by a clinical world of evidence-based practice, scientific truths, and cynicism prompted by patients' dynamic storytelling. As Shapiro (2011) observes,

> From the clinical perspective, while diagnostic technologies are widely regarded as objective and replicable, patient stories can change in both content and emphasis from one telling to the next and therefore may be seen as problematic, especially when they are resistant or oppositional narratives. (p. 68)

While stories are not entirely uninfluenced by external forces, and in some cases writing prompts (i.e., "tell me about your illness"), stories that push the formal boundaries of narrative construction, that are a response to illness or life in a hospital or a perceived life without illness, can be authentic.

> A brutal, unremittingly ugly narrative is not necessarily a more "real" narrative than a transformative one . . . no matter how incomplete, flawed, transgressive or unexceptional, [the story] still merits respect and empathy because ultimately it belongs to the patient and represents the patient's truth in that specific iteration. (Shapiro, 2011, p. 69)

Narrative medicine in general gives providers the tools to provide holistic care, tolerate and manage uncertainty, alleviate burnout, enhance communication, identify and deliberate ethical problems, and foster a sense of community (Lanocha, 2021). In referencing DasGupta's concept of "social voicelessness" among pediatric populations, Lanocha (2021) writes (p. 7),

> we are accustomed to searching for narratives among the silences . . . [Thus] with its natural emphasis on structure, pattern, and silence, poetry can be a valuable tool to teach providers to identify emotive subtleties, and has been effective in teaching narrative competence among pediatric trainees. . . . Targeting training to emphasize certain skill sets can help promote competence in identifying patients' fears and needs, even when they cannot speak for themselves (p.7).

See the poem "Don't Label Me" below where we give our pediatric writers the last word. Herein lies the need to acquire all types of stories, including those written or told in poetic form. The authenticity of these stories can be identified in their very lack of formal narrative structure and in those captured moments that give us genuine insight into a patient's feelings, thoughts, and relationships, including their journey of illness, recovery, and transformation, without revision or refinement. As Shapiro (2011) observes, even stories that lack narrative structure communicate important truths and should be approached with honor and humility. Thus, we present the stories of children and young adults, captured through poetry and prose, where the line between fiction and nonfiction is often blurred. These stories at times lack those elements that define such stories as "narratives," but they are authentic. The acts of storytelling and poetry writing have provided pediatric patients an opportunity to gain control of their environment and illness—if only for a moment—and to offer us a glimpse of who they are, how they are coping, and why it matters.

Study Limitations

This study is limited by its retrospective design utilizing a convenience sample. Other than age ranges, we did not collect valuable demographic data, including race/ethnicity, the nature of subjects' medical condition, disability or illness, the number of hospitalization days, and the outcome of their care or survivability. Had we the opportunity to collect this demographic and clinical information, we could have completed an even deeper analysis correlating the demographics to the types, elements, and content of the stories. Nevertheless, becoming immersed in these pediatric stories from two cohorts has garnered important results and insights that can inform caregivers and fuel future research within this scope of mixed methodology. For some ETC individuals the writing intervention was less than the 50-minutes allocated for the PHP group. The time discrepancy most likely did not have a significant impact on participants' actual writing time, since part of the 50-minute PHP time involved listening to peers' stories. In addition, the data were cross-sectional in that texts were created and collected at one point in time per individual. We are unable to examine the texts to see how narratives changed over time. Despite these limitations, this study offers multiple insights into pediatric storytelling through poetry and prose, particularly through the quest-like narratives.

Conclusion: Implications for Practice and Future Directions

Historically, research on illness narratives has been on adult patient populations and on storytelling that speaks directly to the illness experience. Until more recently, illness narratives among pediatric and young adult populations, and storytelling that lies on the periphery of the illness experience but is relevant to the patient's presentation, have not been examined through mixed methods research. Pediatric and young adult populations do not always explain what it is like to experience an illness directly, but rather present their observations on the hospital, relationships among family, providers, and others, interests and values that keep them hopeful in their recovery, and learned lessons they wish to impart to with those with similar illnesses, disabilities, or emotional states.

Through our retrospective, mixed-methods study, we have connected Arthur Frank's notable work on illness narratives to the stories told by two populations of hospitalized pediatric patients. We have found the majority of their quest-like stories are symbolically situated in their hopeful, optimistic, and, overall, emotionally positive journeys toward recovery, relationships, and a deeper recognition of the self. We have also found that the stories, particularly told through the use of poetry, concealed, if not personified, illness as impersonal pronouns—the "someone" or "something" that caused illness, disability, or emotional pain. Not only are illness narratives "still at risk of being perceived as untrustworthy, inaccurate, dishonest, or mistaken" (Shapiro, 2011, p. 68), but when they lack formal narrative elements or structure, the authenticity of stories and the objective truths within are questioned. In this paper, we illustrated that pediatric patients present an authentic voice despite lacking the formal narrative structure seen with adult populations.

Training healthcare professionals to experience and assess the stories of their pediatric patients will not only strengthen the therapeutic relationship but also prompt deeper questions and answers to patients' innermost thoughts and feelings. Future research needs to identify the implications of storytelling in clinical practice, and whether care and treatment outcomes could be improved through assessing these valuable and insightful stories. As illness unfolds in stories, we allow the interior lives of patients to be heard. And in the effort to have their voices genuinely understood, our next step is to bring our pediatric patients, their family, and healthcare professional caregivers together to achieve a shared understanding of these important stories, and ultimately whole-person care. However, we must first begin with narrative medicine workshops, caregiver writing interventions, and other opportunities to train healthcare professional caregivers to closely read, reflect, and learn how to receive a medical history rather than simply take one.

Don't Label Me

What you see when you see me
is to your surprise, a lie.
I am someone other.
You take one look,
you judge the book
only by its cover.

but if you opened to the pages
and skimmed just a little bit
your labels and all the judgements
would be broken into bits

You'd be forced to see
that what you see, is not me
but only you
your false perception
you're afraid to open the book
and find your miscorrection

See, that's wrong of me
to assume something about you.
but that's how it seemed
so dear me
had passed that judgment on you.

How does that feel?
Not very nice?
Not very caring?
Not very kind?
Did you get defensive?
Were you offended?
Because that's how I feel everyday
when I try to pass you as an individual
and get a label thrown in my way.

—Adolescent patient

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