Pediatric Narrative Oncology: Interprofessional Training to Promote Empathy, Build Teams, and Prevent Burnout

Stephen A. Sands, PsyD, Patricia Stanley, MA, and Rita Charon, MD, PhD

The practice of pediatric oncology demands empathy, teamwork, and resilience from doctors, nurses, social workers, and therapists who care for children with cancer. Empathy enables caregivers to recognize patients and their families in full, offering hope and conveying both competence and commitment to them. Teamwork, with its obligatory honesty and trust, allows the multiple professionals to amplify their individual discipline’s power to help ill children. Resilience in caregivers can protect against the burnout and defeat common in this field. Unlike other medical fields in which recovery is common or death sometimes acceptable, pediatric oncology taunts professionals with the random unfairness of serious disease that befalls children. Even with the rise of successful treatment of children with cancer, those who are engaged in providing care can experience guilt and rage and often respond with detachment and withdrawal. The isolated or defeated professional burns out and can help no one, but empathy, teamwork, and resilience can reconnect these caregivers to patients, to colleagues, and to themselves, letting them again deliver effective and nourishing care.

Many medical educators worry that these capacities are difficult to teach. Recent developments in medical education suggest that empathy, teamwork, and resilience may be attainable through training in narrative competence; that is, the capacity to understand stories, to see events through training in narrative competence; that is, the capacity to understand stories, to see events from others’ points of view, to recognize singular persons, and to reflect on one’s experience.

Abstract The aim of this study was to test the feasibility and effectiveness of providing narrative training to a mixed group of doctors, nurses, social workers, and child life therapists on a pediatric oncology service for the purpose of promoting empathy, building teams, and preventing burnout. All staff members were invited to attend a weekly narrative training seminar for 6 weeks. During these seminars, participants wrote about their attachment to patients, their emotional responses to patients and families, and their attempts to imagine clinical situations from the perspectives of patients and family members; participants then read aloud their narratives to one another during a facilitated discussion. Baseline and post-intervention assessments used the Interpersonal Reactivity Index (IRI) and the Stressor Scale for Pediatric Oncology Nurses (SSPON), and a focus group was convened to assess qualitative outcomes at the study’s conclusion. Nineteen staff members who consented and participated in the training completed all baseline and post-intervention measures. THE IRI subset of Perspective Taking improved at a statistically significant level ($P = 0.029$), and the Empathic Concern subset tended toward significant improvement ($P = 0.056$). Reported stress levels on the SSPON increased at varying rates over the course of the study. Focus group reports indicated that teamwork and resilience improved in the 6 weeks of the seminar. A narrative training approach aimed at an inter-disciplinary group of healthcare professionals has promise as a means to address some of the most difficult aspects of pediatric oncology care facing clinicians.

Medicine practiced with such competence is coming to be known as narrative medicine. By providing healthcare professionals with advanced narrative skills, narrative training has been shown to help clinicians listen empathically, build effective therapeutic alliances with patients and colleagues, and reflect on practice and the self. Narrative thinking is also seen as instrumental in diagnostic reasoning, theorizing, ethical awareness, and alliance-building with patients. Narrative interventions in a range of healthcare professions share a theoretical orientation that values narrating as an avenue toward empathy and reflection in clinical work.
Goals of Narrative Medicine

INCREASING EMPATHY

The most highly skilled technical care will not effectively reach the patient unless the provider is equipped with the interpersonal skills to recognize the patient’s situation and join empathically with the patient during care. Medical, nursing, and social work schools, residency training programs, specialty boards, and societies have endorsed the goals of building empathy in practice. Instead of earlier models of training for empathy, conceptualizing it as an emotional state like sympathy or pity, recent efforts focus on the shifting of perspective necessary for one person to be able to imagine the situation of another. Less an affective than a cognitive and imaginative goal, empathy can be nurtured by helping health professionals to perceive, describe, and then behold the singular situations of their patients. Once the patient has been illuminated by this shift in perspective, the healthcare professional is in a position to witness the suffering and courage of persons in his or her care and develop authentic relationships with them.

BUILDING TEAMS

Because contemporary oncology practice demands well-functioning multidisciplinary teams, cohesiveness and shared commitment to expert clinical care must be maintained. Highly stressed professionals often remain within their own culture—doctors talk to doctors, nurses to nurses, and social workers to social workers—to deal with the emotional tolls of care in the face of extraordinary stress. Although mechanisms exist for interdisciplinary clinical rounds, the individual professionals rarely share their own personal or emotional plights with members of the team in other professions. As a result, the team can fracture along disciplinary lines, and the individual professionals’ perspectives often clash. Adding to the suffering of patients and their families are the often poorly masked disagreements among team members about the optimal course of action, leading to inefficiency and error.

STRENGTHENING RESILIENCE AND REDUCING BURNOUT

Burnout is a response to chronic emotional stressors on the job and is defined by exhaustion, cynicism, and inefficacy in the workplace. Aspects of such jobs in healthcare, including technically demanding care, gravely ill patients, prevalence of negative outcomes, and a scarcity of resources, predict high levels of burnout and characterize inpatient pediatric oncology. Burnout has been associated with negative changes in job performance such as absenteeism, intention to leave the job, increased personal conflict, and reduced effectiveness and may lead to more serious consequences, including depression and substance abuse. These findings have direct consequences on the quality of patient care, as a number of studies have found a direct relationship between medical staff turnover and risk-adjusted mortality scores, severity-adjusted length of stay, and medical errors. Several studies have reported a high incidence of burnout, depression, anxiety, low self-esteem, and sense of failure among US oncologists. The nursing literature also finds that oncology nurses experience greater-than-normal levels of despair, social isolation, and somatization. Doctors and nurses with higher levels of burnout are found to communicate less effectively with patients.

Materials and Methods

The pilot study reported here was designed as a feasibility and effectiveness study of interdisciplinary training for pediatric oncology healthcare professionals to test the acceptability and effectiveness of narrative training for these groups. By asking clinicians to write about their practices, the training sought to increase their ability to represent and therefore perceive complex situations. By asking participants to read aloud their narrative to one another during facilitated discussions, the training process enabled them to recognize one another’s perspectives on illness. By training them together, the pilot sought to decrease the divides between professionals and to enable them to grow in all aspects of our goals—empathy, teamwork, and resilience—in a skills-based and collegial format.

Pediatric Narrative Oncology was open to all healthcare professionals who staff the pediatric oncology in-patient unit at the Morgan Stanley Children's Hospital of New York-Presbyterian (New York, NY). Each doctor, nurse, and psychosocial clinician were invited to attend six weekly sessions over the course of the study. Separate weekly sessions were offered for both the day and night shifts. Although the membership of each session varied due to changes in staff scheduling, there was always a mix of disciplines present. Two faculty members—an internist with literary training and a patient advocate and scholar of illness narratives—served as facilitators, or writing coaches, for the seminars.

The 60-minute seminars began with 10 minutes of silent writing in answer to a prompt given by the coach. Participants were sometimes asked to write a description of a patient or family whose suffering had moved them. They were sometimes asked to write from the point of view of a patient, family member, or other healthcare professional. Participants were then invited to read aloud what they had written. The coach began the discussion of each text, usually with comments about the writing itself—the genre, images, language, narrative structure, time course, or how this text differed from earlier texts by the writer. Other members of the group were then invited to share their thoughts and feelings about what they had heard. Because many participants in addition to the writer knew the patients and families described, there was usually spirited conversation about both the patient and his or her narrative representation.

At the close of the seminar, the coach collected the participants’ texts and made written comments on the papers for distribution at the next session. In this way, private conversations between participants and coaches developed during the seminar.

PARTICIPANTS

The 19 participants worked on the pediatric oncology in-patient unit during the period of intervention and completed both
Motor events and conditions that can alter a pediatric oncol-

Vo l u m e 6, Nu m b e r 7

Spinella et al showed that the four scales have reasonable psy-

o l o g y emotional or cognitive state and thereby produce physical or psychosocial reactions. The SSPON uses a visual ana-

logue format comprising horizontal lines through which the respondent is asked to draw a straight line for each statement ranging from “not at all stressful” (0) to “as stressful as can be” (1000). The SSPON examines six factors: Co-worker Incom-

p t ence: perception of co-workers’ insensitivity towards patients’ conditions or incompetence in professional tasks; System De-

m ands: competing role-related tasks, contending priorities,

SAMPLE #1: ONCOLOGIST

They are not your run-of-the-mill family, although I guess they are just one more version of the “not happy” family cat-

t egory. Drug abuse, alcohol abuse, rotating relationships de-

fine the adulthood of both parents. The boy morphing into a man with the cancer eating away at his bones inherited most of the habits. These are habits that have stayed around for the year of chemotherapy, probably helping sometimes. Most of the time they struggle against one another. But today with the cancer back, they are more together than I have ever seen them. Their fear and pain bind them togeth-

er, make them more like a family, but still not a happy one.

SAMPLE #2: SOCIAL WORKER

Watching him run in the clinic with his backpack of TPN (total parenteral nutrition) attached to him, it brings a huge smile to my face and I am amazed at how far he has come since his transplant. A few months ago he was in and out of the hospital constantly, never smiling, and at high risk for potentially fatal complications. There were times when the end seemed near. Now he is a little boy acting like a little boy, which is a miracle. The unfortunate twist is that he is not living at home with his family. And he seems to have flour-

ished in his new environment at [the rehabilitation hospita-

l]. What will happen when he returns home? For now, I look forward to his smile and interaction and think just how far he has come both medically and socially.

SAMPLE #3: NURSE

My patient is a lovely, preteen girl. Her mother and aunt are attractive, pleasant, and most polite. And gracious. Most patients look relatively healthy, although bald and con-

nected to wires. They still look like average kids, playing videos and watching TV. My patient is forced to wear her cancerous growth on her face. Over the past 2 weeks, the growth seems to be getting larger and uglier. She can barely breathe as the growth has completely covered her nose and part of her mouth. She can only lie in bed and cry. Is it pain, or just sorrow? Perhaps a bit of both. I gave her a DVD—Lizzie McGuire movie, and she laughed, just like my child would have. I know that everything is being done to help this girl, and I wonder at an existence, which we all share, that could allow such outward and inward suffering. I am always amazed at the graciousness of her mother whenever I do her a small favor. I wonder how she can continue in this way, and how it will end, ultimately.

THEME:

Fantasy:

the use of imagination to expe-

rience the feelings of others; Empathic Concern: the regard for another’s feelings; and Personal Distress: the anxiety and dis-

comfort in the face of another person’s negative experience. Spinella et al showed that the four scales have reasonable psy-

chometric properties.

The SSPON measures the internal and external environ-

mental events and conditions that can alter a pediatric oncol-

ogy...
ineffective teamwork, and time constraints; Knowing What Is Ahead: awareness of impending difficulties and suffering for patients; Limits of Care: awareness and frustration for the limitations in relieving patient suffering; Emotional Demands: the personal stress endured by professionals regarding patient care and execution of tasks; and Death Without Grace: belief that patients do not die a gentle death.

Results
Pre- and post-IRI questionnaire responses (n = 19) were analyzed using a paired t-test and indicated that the participants demonstrated an increased ability for Perspective Taking over time (P = 0.029). This difference included healthcare professionals of all disciplines and was not dependent on their years in the field. There was also a trend toward significance of improvement in the Empathic Concern rating (P = 0.056), although there were no significant changes from baseline to post-intervention within the domains of Fantasy or Personal Distress (Table 1).

Analyzing the pre- and post-intervention SSPON ratings with paired t-tests indicated that all the mean scores increased at various levels from baseline to follow-up, revealing an increase in perceived level of stress over time. Specifically, the participants reported significant increases in the level of stress reflected by the Death Without Grace score (P = 0.008) and Co-Worker Incompetence score (P = 0.022), whereas the remaining domains did not (Table 2).

Analyzing the SSPON responses of 18 physicians and nurses who completed the pre and post-assessments using a t-test analysis indicated that nurses reported a higher level of stress around the System Demands than did the physicians (P = 0.018) after the intervention, whereas both disciplines reported similar levels of distress on all other five domains at both pre- and post-assessment. Additionally, a similar analysis between the responses of the two disciplines on the IRI did not demonstrate any statistical significance between doctors and nurses, with the exception of an increase in the Fantasy scale for physicians at time 2 (P = 0.017; Tables 3 and 4).

FOCUS GROUP REVIEW
A focus group of 14 participants was convened by a member of the educational research division at Columbia University Medical Center in the last week of the intervention. The focus group participants observed that the Pediatric Narrative Oncology seminar was a special experience that allowed individuals to consider, evaluate, and express their everyday experiences through writing and meaningful communication with one another. Individuals reported that the experiences they examined in the narrative seminar were experiences they otherwise would not have reflected upon. Many participants stated that they encountered professional perspectives that they were not aware their colleagues held. Three themes emerged from this 1-hour focus group.

1) The seminar revealed new aspects of the self of the individual writer. Narrative seminars were found to differ from “just talking.” Participants discovered that to write reflectively about an experience, they had to undergo an introspective process whereby they exposed themselves and their experiences in a new manner. Individuals reported both positive and negative feelings about doing so. They indicated that sharing the writing within the seminar was an important component in this process.

2) Participants observed that the responsiveness of the writing and sharing process transferred to the interpersonal interactions of team members outside the focus group setting and in the natural work environment. For example, upon encountering a particular child who was discussed in the seminars, some participants would reflect thoroughly on the patient’s needs and on the context of that child’s condition and care. Others reported being far too busy to have time to “think” and that the only place to do such reflective activity was in the groups. A number of individuals reported learning more and gaining insight about other members of their groups, such as where they came from, their professional perspective, and their level of caring.

Table 1
Baseline and Follow-Up IRI Scores (n = 19)

<table>
<thead>
<tr>
<th>FACTORS</th>
<th>BASELINE MEAN (SD)</th>
<th>FOLLOW-UP MEAN (SD)</th>
<th>CHANGE</th>
<th>P VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perspective Taking</td>
<td>2.6 (0.63)</td>
<td>2.9 (0.59)</td>
<td>0.029</td>
<td></td>
</tr>
<tr>
<td>Fantasy</td>
<td>2.0 (1.1)</td>
<td>2.1 (0.97)</td>
<td>0.629</td>
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<tr>
<td>Empathic Concern</td>
<td>3.3 (0.45)</td>
<td>3.2 (0.63)</td>
<td>0.056</td>
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<tr>
<td>Personal Distress</td>
<td>1.3 (0.54)</td>
<td>1.1 (0.44)</td>
<td>0.147</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2.3 (0.44)</td>
<td>2.3 (0.42)</td>
<td>0.508</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviation: IRI = Interpersonal Reactivity Index

Table 2
Baseline and Follow-Up SSPON Scores (n = 19)

<table>
<thead>
<tr>
<th>FACTORS</th>
<th>BASELINE MEAN (SD)</th>
<th>FOLLOW-UP MEAN (SD)</th>
<th>CHANGE</th>
<th>P VALUE</th>
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</thead>
<tbody>
<tr>
<td>Co-worker Incompetence</td>
<td>634.01 (209.35)</td>
<td>704.91 (167.13)</td>
<td>+70.90</td>
<td>0.022</td>
</tr>
<tr>
<td>System Demands</td>
<td>598.85 (148.57)</td>
<td>645.92 (145.49)</td>
<td>+47.07</td>
<td>0.142</td>
</tr>
<tr>
<td>Knowing What Is Ahead</td>
<td>556.82 (149.12)</td>
<td>595.79 (151.9)</td>
<td>+38.97</td>
<td>0.267</td>
</tr>
<tr>
<td>Limits of Care</td>
<td>673.13 (132.71)</td>
<td>682.60 (109.7)</td>
<td>+9.48</td>
<td>0.651</td>
</tr>
<tr>
<td>Emotional Demands</td>
<td>525.19 (159.87)</td>
<td>584.71 (123.78)</td>
<td>+59.53</td>
<td>0.059</td>
</tr>
<tr>
<td>Death Without Grace</td>
<td>574.66 (246.7)</td>
<td>690.00 (171.33)</td>
<td>+115.34</td>
<td>0.008</td>
</tr>
</tbody>
</table>

Abbreviation: SSPON = Stressor Scale for Pediatric Oncology Nurses
3) Participants observed that the structure and timing of the narrative seminar need to be carefully considered so as not to conflict with clinical duties.

**Discussion**

This pilot study demonstrated the feasibility of being able to provide a brief staff intervention on a busy inpatient medical unit where participants from a range of specialties united to write about their attachment to patients, their emotional responses to patients and families, and their attempts to imagine clinical situations from the perspectives of patients and family members.

The hypothesis that narrative training can increase empathy was supported by the significant increase in Perspective Taking scores and the near-significant increase Empathic Concern scores on the IRI. The team-building hypothesis of the study was supported by the focus group reports of transactions that emphasized the dividends for individual participants of learning about one another as people and glimpsing into their perspectives on the care of children on the unit. The participants also observed, even in this short feasibility study, that the relationships nurtured in the seminar "spilled over" into the team’s function on the unit. Additionally, the activity of narrative writing was found by participants of various professional disciplines to be useful and even pleasurable. Participants found that it improved their ability to reflect on their work and their understanding of their team members.

The findings of the SSPON suggest that stress levels do not decline over time by virtue of this intervention. This is not a bandage for suffering or a salve for stress. Instead, the writing may make participants, if anything, more aware of the unfairness and the suffering encountered in pediatric oncology. However, the intervention provides some commonality of the experiences of caring for dying children, as suggested in the nearing of scores among doctors and nurses, potentially leaving a more cohesive and attentive healthcare team in its wake.

**Conclusion**

These findings suggest that narrative training for interdisciplinary groups of healthcare professionals may be a promising method for improving both the clinical care provided and the lived experiences of the professionals. Future work will require larger samples to validate the findings, more rigorous outcomes measures in team-building and preventing burnout, and extended follow-up measures of healthcare professionals’ resilience and commitment to clinical work.

**Acknowledgments**

We acknowledge the contribution of all participants in this pilot study, without whose generosity and creativity this work would not have been possible.

**Table 3**

SSPON Scores by Physician and Nursing Professions (n = 18)

<table>
<thead>
<tr>
<th></th>
<th>PHYSICIAN (n = 6) MEAN (SD)</th>
<th>NURSE (n = 12) MEAN (SD)</th>
<th>P VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-worker Incompetence</td>
<td>586.56 (267.11)</td>
<td>688.35 (150.24)</td>
<td>0.129</td>
</tr>
<tr>
<td>System Demands</td>
<td>618.72 (137.8)</td>
<td>623.59 (104.24)</td>
<td>0.326</td>
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<tr>
<td>Knowing What Is Ahead</td>
<td>562.50 (174.31)</td>
<td>580.79 (111.88)</td>
<td>0.240</td>
</tr>
<tr>
<td>Limits of Care</td>
<td>696.11 (135.36)</td>
<td>684.64 (114.58)</td>
<td>0.676</td>
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<tr>
<td>Emotional Demands</td>
<td>564.05 (206.28)</td>
<td>527.95 (123.29)</td>
<td>0.258</td>
</tr>
<tr>
<td>Death Without Grace</td>
<td>567.92 (260.63)</td>
<td>569.67 (260.29)</td>
<td>0.990</td>
</tr>
<tr>
<td><strong>Time 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-worker Incompetence</td>
<td>634.44 (199.04)</td>
<td>749.44 (147.29)</td>
<td>0.133</td>
</tr>
<tr>
<td>System Demands</td>
<td>611.69 (212.59)</td>
<td>678.47 (95.83)</td>
<td>0.018</td>
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<tr>
<td>Knowing What Is Ahead</td>
<td>569.67 (160.11)</td>
<td>612.00 (159.11)</td>
<td>0.755</td>
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<tr>
<td>Limits of Care</td>
<td>671.14 (130.82)</td>
<td>693.07 (106.92)</td>
<td>0.419</td>
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<tr>
<td>Emotional Demands</td>
<td>588.65 (164.03)</td>
<td>592.23 (107.67)</td>
<td>0.145</td>
</tr>
<tr>
<td>Death Without Grace</td>
<td>728.33 (194.16)</td>
<td>682.50 (168.1)</td>
<td>0.965</td>
</tr>
</tbody>
</table>

**Table 4**

IRI Scores by Physician and Nursing Professions (n = 18)

<table>
<thead>
<tr>
<th></th>
<th>PHYSICIAN (n = 6) MEAN (SD)</th>
<th>NURSE (n = 12) MEAN (SD)</th>
<th>P VALUE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perspective Taking</td>
<td>2.69 (0.62)</td>
<td>2.55 (0.68)</td>
<td>0.673</td>
</tr>
<tr>
<td>Fantasy</td>
<td>2.64 (0.92)</td>
<td>1.75 (1.1)</td>
<td>0.111</td>
</tr>
<tr>
<td>Empathic Concern</td>
<td>3.33 (0.49)</td>
<td>3.38 (0.47)</td>
<td>0.828</td>
</tr>
<tr>
<td>Personal Distress</td>
<td>1.43 (0.47)</td>
<td>1.34 (0.6)</td>
<td>0.743</td>
</tr>
<tr>
<td><strong>Time 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perspective Taking</td>
<td>2.95 (0.48)</td>
<td>2.89 (0.63)</td>
<td>0.841</td>
</tr>
<tr>
<td>Fantasy</td>
<td>2.91 (0.72)</td>
<td>1.79 (0.9)</td>
<td>0.017</td>
</tr>
<tr>
<td>Empathic Concern</td>
<td>3.22 (0.7)</td>
<td>3.23 (0.54)</td>
<td>0.971</td>
</tr>
<tr>
<td>Personal Distress</td>
<td>1.12 (0.57)</td>
<td>1.09 (0.4)</td>
<td>0.898</td>
</tr>
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</table>

Abbreviation: IRI = Interpersonal Reactivity Index
References

PubMed ID in brackets

15. Jordens CF, Little M. “In this scenario, I do this, for these reasons”: narrative, genre and ethical reasoning in the clinic. Soc Sci Med 2004;58:1635–1645. [14993066]
32. Souba WW. Academic medicine and the search for meaning and purpose. Acad Med 2002;77:139–144. [11841973]
This report supports the American Academy of Pediatrics clinical report “Overuse Injuries, Overtraining, and Burnout in Child and Adolescent Athletes.” This clinical report replaces a previous American Academy of Pediatrics (AAP) policy statement entitled “Intensive Training and Sports Specialization in Young Athletes” and is complementary to the AAP clinical report “Overuse Injuries, Overtraining, and Burnout in Child and Adolescent Athletes.” This report reviews the epidemiology of youth sports and the background of specialization, highlights specific physiologic concerns with intensive training, answers.