

# Half As Sad: A Plea for Narrative Medicine in Pediatric Residency Training

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## THE FOLLOWING IS FROM THE PERSPECTIVE OF C.D., NOW A HEMATOLOGY/ONCOLOGY FELLOW

During my third year of general pediatrics residency training, a patient well known to me and my fellow residents died unexpectedly. The child was an extremely bright and mature 8-year-old who had spent much of the last year of her life in our hospital being treated for cancer. Seemingly overnight, she became “too” sick (ICU sick, intubated and ventilated, on dialysis sick). She began to have intractable seizures, and with her family by her side, she died.

The next morning, a colleague in his first year of residency asked how I was. I said that it had been a difficult week and I felt profoundly sad about the death of our patient. A look of relief came over his face. He told me that he was feeling despair. This was the first child he had cared for that had died. He had never felt such sadness before and felt guilty for feeling sad. He said that in medical school he had been told by a senior physician that it was the professional responsibility of a physician to “never feel more than 50% as sad as a patient’s family.” Faced with the reality of the death of a child, my colleague was left feeling confused, distressed, and disenfranchised from his own emotional response.

## THE FOLLOWING IS FROM THE PERSPECTIVE OF M.N., NOW AN ATTENDING PEDIATRICIAN-GENETICIST, REFLECTING ON HER OWN EXPERIENCE DURING RESIDENCY 20 YEARS AGO

“You put on the waterworks and it makes the parents feel better,” my genetics attending said. She seemed proud to have arrived at this simple remedy. She had just finished counseling a couple whose child had been diagnosed with a lethal genetic condition. Were the tears an act simulating empathy for the parents? Or were the words simply posturing to cover up real feelings of helplessness and emotional vulnerability? I never found out.

This was the reality of training 20 years ago; one did not admit one’s feelings because it was deemed unprofessional. Gallows humor and cynicism shielded us from grief and sorrow. I conformed and, as a result, for years I did not process my own feelings of sadness and despair. It was not until 12 years later, after I had diagnosed and counseled >200 patients and their families, that the avoidance of my emotional experience took its toll. Compassion fatigue overwhelmed me.

## JOINT REFLECTION OF C.D. AND M.N.

How are we supposed to cope with the profound sadness we feel when one of our patients dies? Or when we diagnose a patient



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with a life-altering condition? And what tools are we given to learn this very human skill? A resident cannot quantify the sadness he or she feels when a child dies or pretend not to have an emotional response. We need to learn strategies to process the emotional content of our interactions with patients and their families, particularly in the face of tragedy.

Narrative medicine is a practice that shows promise for helping clinicians renew and develop their empathy and compassion. It is an approach to medicine that emphasizes understanding the narrative elements of patient and provider stories.<sup>1</sup> With a focus on close reading of texts and reflective writing, narrative medicine is a movement that has emerged in undergraduate medical education.<sup>1,2</sup> Using techniques not traditionally offered by an evidence-based learning paradigm, narrative medicine aims to help learners appreciate and understand their relationships with patients by studying the literary underpinnings of patients' stories.<sup>3</sup> This may be achieved by providing learners with the opportunity to discuss literary works or to express their own experiences through writing.

Discussion of literary works allows for the exploration of narrative. Narrative operates on a deeply personal level. It integrates large concepts such as life, death, and purpose with individual characters.<sup>4</sup> By offering a means to engage on a deeper level with patients and their stories, narrative inquiry can encourage residents to challenge assumptions, values, and even self-perception in a nondidactic, nonprescriptive way. Narrative medicine also helps train residents to tolerate uncertainty.<sup>5,6</sup> Studying the humanities helps learners see from different perspectives and stimulates the development of increased insight and articulation.<sup>7</sup> Reading literary fiction has been shown to improve theory of mind:

the capacity to see from a perspective other than one's own and the insights gained from such an experience.<sup>8</sup> Theory of mind is a critical cognitive component of empathy, the ability to walk in another person's shoes or see from his or her point of view.<sup>9</sup> Exploring literary works together and finding meaning therein offers the opportunity not only to deepen personal understanding but to create a protected environment in which residents and attending physicians can learn from one another.<sup>2</sup>

At its core, the study of narrative medicine is about stories. Stories are fundamental to the practice of medicine; without the patient's story, we cannot proceed with diagnosis or treatment. But tension exists in the current postgraduate training paradigm between the desire and obligation to honor patients' experiences as individuals and the requirement to reduce stories to ever more succinct snippets to facilitate efficient diagnosis, charting, and handover. For example, a resident may spend an hour sitting with the family of a child newly diagnosed with leukemia, exploring their feelings of guilt and despair, the fear that they had failed to recognize that their child was ill, and their terror about what chemotherapy might bring. At handover, this experience is necessarily reduced to "3-year-old boy, new diagnosis of leukemia. Currently stable. Started induction chemotherapy today. At risk for tumor lysis." Although we are trained over many years to give concise presentations, we are not trained to process the narrative content of the multifaceted relationships we have with patients and families. This reduction of complex emotional experiences to brief, dispassionate retellings occurs daily. The consequence for the physician may be desensitization or maladaptive behaviors. If we are to see a patient's illness through a literary lens, narrative medicine offers the

opportunity to discuss not just the plot (new diagnosis of leukemia) but the tone, the voice, the texture, and the lived experience from which that information arose.<sup>5</sup> This reengagement with other elements of the physician-patient interaction may allow the clinician to become more compassionate with their patients and cultivate insights into their own actions and reactions.

To facilitate this discussion of narrative in the context of caring for patients, we have developed a literary companion curriculum for pediatric residents at our institution, consisting of 2 mandatory 1-hour sessions included in our professional competencies curriculum. The first session is a didactic lecture exploring the concepts of narrative medicine. This session provides an introduction to close reading, that is, reading with careful attention to content, style, language, and pace.<sup>10</sup> In the second session, residents are invited to engage with specific pieces of literature in a small-group setting facilitated by attending physicians and senior residents. Learners are provided with short works and sample questions for discussion in advance of the session and are empowered to discuss the works that resonated with them the most. We also offer a suggested reading list of fiction and nonfiction works related to pediatrics, organized by rotation. For example, we suggest that pediatric residents read "People Like That Are the Only People Here: Canonical Babbling in Peed Onk" by Lorrie Moore during their pediatric surgery rotation and "The Ones Who Walk Away from Omelas" by Ursula K. Le Guin during their social pediatrics rotation. Even this modest foray into the humanities may offer residents an essential set of tools for coping with the challenges of pediatric residency.

More extensive medical humanities programs have been implemented for

physical medicine and rehabilitation and family medicine residents, and these have been received positively.<sup>7</sup> Humanities programs have also been suggested for psychiatry trainees.<sup>11</sup> Although empirical evaluation of the impact of humanities-based programs is difficult, a recent study revealed an improvement in empathy in staff physicians who participated in a reflective writing course,<sup>12</sup> and in pediatrics, narrative medicine has been suggested as a tool to address physician burnout during residency training.<sup>13</sup>

Caring for pediatric patients is incredibly rewarding and exquisitely difficult. The biomedical paradigm in which we are so well trained fails to prepare us for the emotional exigencies of being a physician. We must move beyond proscribing what fraction of emotional expression is considered professional to feel and instead focus on training caregivers to cope effectively with tragedy and stress. Narrative medicine offers a means of processing clinical experience beyond the quantitative

and opens a forum to explore our collective humanity.

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