

## PERSPECTIVE



# Narrative neonatology: integrating narrative medicine into the neonatal intensive care unit

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*You hang up the telephone and rush towards labor and delivery. You see obstetrical residents pushing a woman towards the operating room. Blood seeps through the white blanket draped over her legs and drips onto the floor. She is screaming. A nurse runs by shouting that the patient's due date is 16 weeks away. You rush alongside the gurney to tell this woman that you, the doctor for her baby, are there to care for her child. As nurses and doctors move her onto the operating room table, you ask if her son has a name. "Save Kathan," she whispers. Then the anesthesiologist places a mask over her face, and you rush to set up your stabilization equipment.*

Every day in the neonatal intensive care unit (NICU), stories are told and retold. Using formats engrained in medical school, clinicians recount why each baby is in the NICU and what events occurred in the past day. With successive years of training and experience, these stories are told in a brief, ritualistic manner. But others in the unit hear – and tell – stories, too.

Parents bring a history rich in its narrative insight if we but ask...and listen. How do we assist this baby towards a healthy discharge? And what story will be told of the arduous path in the NICU by parents, who are shaped by their time in the NICU [1]? How do we attend to the stories of nurses safeguarding patients while dealing with their own anxieties, risks of moral distress and burnout? [2] Our tiny patients are unable to speak yet the stories they tell are humbling [3]. Our trainees, processing neonatal death while rotating in the NICU, turn to literature to help make sense of tragedy [4]. At times, we anticipate the devastation wrought from life-limiting fetal anomalies and help families craft stories [5]. As clinicians process and sift through and interpret these stories, we also tell our own stories [6–8]. Sometimes parents and neonatologists tell different stories about identical patients [9]. The words chosen to craft these stories impact relationships between parents and neonatologists [10].

Stories matter. "We tell ourselves stories in order to live [11]," author Joan Didion proclaimed. Just as stories matter in life, they matter in medicine. The overlap between medicine and humanities is thousands of years old, predating the humoral medicine advocated by Hippocrates and the shift to considering medicine as science formalized in the Flexner Report [12]. The Association of American Medical Colleges' formalized a recommitment to medical humanities in graduate medical education in 2020 [13]. The remainder of this article focuses on a specific genre of medical humanities, narrative medicine, and its published and theoretical overlay with neonatology.

## DEFINING NARRATIVE NEONATOLOGY AND BRIEF OVERVIEW OF NARRATIVE MEDICINE THEORY

Narrative medicine, defined by Rita Charon as "medicine practiced with the narrative competence to recognize, interpret, and be moved to action by the predicaments of others," [14] aims to help clinicians attend to the stories embedded in our work [15] and by extension provide respectful, empathic and fulfilling medical care [16]. Much of the case for narrative medicine, and the majority of its evidentiary and theoretical grounding, has been made outside the NICU. As narrative medicine gains traction in the media [17, 18] and pediatrics [19, 20], bringing this practice into the NICU is a natural next step. We propose coining the integration and application of narrative medicine into the NICU as "narrative neonatology." Narrative neonatology may be seen as the acknowledgment and close reading of stories told by all NICU patients and caregivers.

Narrative medicine strives to help practitioners focus on attention and affiliation [21]. This is done by having practitioners of narrative medicine practice closely reading, synthesizing, and reflecting on literary texts, practitioners of narrative medicine fine tune their attention and ability to listen. Reflective writing allows practitioners of narrative medicine to practice self-awareness by committing to their own vantage of a clinical situation and then using their writing and revision to gain insight into their emotional responses those situations.

Sharing narrative medicine stories in a small group setting, where skilled facilitators provide a supportive, safe atmosphere to navigate intense conversations, may also teach self-awareness [22]. Narrative medicine seminars that encourage writing reflexively and sharing that writing, as well as discussion seminars where facilitators teach close reading of published stories may provide an approach to help clinicians recognize and manage feelings associated with challenging situations [23] or patients.

Narrative medicine allows clinicians to develop a deeper understanding of experiences of patients and families beyond the mere technical, biomedical, and quantitative [19] by enriching the reductionistic, dispassionate way in which patients and their illnesses are often described in healthcare (that promote desensitization and maladaptive behaviors).

Using the techniques of narrative medicine to acknowledge differing perspectives of a given patient or situation and providing close attention to the language used and not used to talk about those clinical moments, clinicians can develop the ability to

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challenge assumption and values, tolerate uncertainty, view a situation from different perspectives, and develop greater insight and better articulation [24–27]. Ultimately these techniques can lead to more empathy and compassion.

### INTEGRATING NARRATIVE MEDICINE INTO THE NICU

How to integrate narrative medicine into the NICU may not seem intuitive. Those providing medical care to adults can listen to patients recount their symptoms and suffering with a narrative lens [16]. Clinicians in the NICU must learn to listen to stories differently. Stories in the NICU are a compilation and collection of perspectives. As neonatal clinicians, we must master the integration of these perspectives to provide holistic care.

Narrative neonatology can take many forms. Reflective writing, formal humanities seminars, visual teaching strategies, reading and contemplating patient or parent stories of healthcare, attending story telling events for clinicians, and our own internal processing of patient care are some of these forms.

#### Reflective writing

The catharsis found in reflective writing helps find meaning by reframing or retelling any story of illness, including neonatal stories [16]. Reflection also breaks down the professional detachment cultivated to work in the NICU. Reflective writing can be solitary, by making time to write about patient stories [28], or it can occur in hospital-based workshops [21, 29, 30], Internal medicine residents taught the craft of creative writing self-report improved patient relationships, self-awareness and compassion [31]. A longitudinal practice of reflective writing for NICU trainees unearths conflicts during provision of care, distress surrounding dying babies, and provides a forum for trainees to grapple with their own morality [32]. Burnout decreased for obstetrical residents participating in narrative medicine writing workshops; [33, 34] there is every reason to believe these workshops could also decrease burnout for neonatal clinicians.

#### Humanities seminars

Narrative neonatology may occur as seminars held in place of didactic lectures [33]. In these seminars, a facilitator selects a poem, prose reading for close reading, or she presents a painting or video to underscore the value in diverse viewpoints of a singular or serial image(s) [16]. In the latter instance, recent evidence points to the presentation of clinical images as open interpretive pieces to engage others in shared reflections, insights, and ascribed meaning(s) of what they “see”, hence improving others’ understanding [35]. These group discussions promoted teamwork and collegiality while allowing the sharing of emotions [30, 36]. Narrative medicine seminars for pediatric residents rotating in neonatal intensive care units provided fulfilling and meaningful forums for shared emotion and group reflection [23].

#### Reading patient and parental stories of neonatal intensive care

Narrative neonatology may manifest as an internal reflection on patient and parental stories. Reading nonmedical literature fostered clinician empathy by allowing the clinician-as-reader to see the world through the perspective of the narrator [37]. Parent stories reflecting on experiences of neonatal care abound in literary magazines [38], memoirs [39], and newspapers. The more clinicians read these stories, the more we can integrate parental perspectives into our work in the NICU.

#### Story telling events

Narrative neonatology may also manifest as storytelling events. Storytelling events are a forum for clinicians to gather and share their own stories of providing patient care. These events fostered

community, re-connection with the meaning of healthcare, and nurture resilience [40].

#### Mindful narration of clinical cases

Narrative neonatology is also present within and between the data of our patients’ day-to-day care. As clinicians sift through labs, vitals, and imaging studies to discern infections, prescribe treatments, wean ventilators, and advance feeds, we narrate. This narration often utilizes the dialect of electronic medical records and rounds presentations. This dialect is replete with Latin terminology, depersonalized descriptions of diseases or diagnoses, and myriad NICU-specific abbreviations: TPN, BPD, ROP, PDA. While this communication is comprehensible to other clinicians, it is often incomprehensible to our patients’ families.

Training ourselves to narrate our patients’ clinical histories without this medical dialect shifted internal narratives to provide more humane, interpretable language when counseling parents [41]. Instead of thinking, “*he is an ex-24-weeker delivered via Stat C-section for placental abruption with respiratory failure and pressor-dependent hypotension,*” we may tell ourselves, “*he is alive in our NICU because his mother, the paramedics, the obstetricians and our colleagues saved his life.*” Narrating such snapshots is another way to integrate narrative medicine into the NICU [42] and may modify the mystical technical jargon abundant in the NICU into a more family-friendly language that enhances understanding and facilitates clear communication.

#### BENEFITS OF NARRATIVE MEDICINE

Burnout is well-characterized for those providing modern medical care; the exact underpinnings are both specific to the NICU environment and universal with respect to the moral injury of modern healthcare [43]. Constantly framing and reframing neonatal care as miraculous can be taxing. At times, our patients’ stories become stories of infant suffering [44] or nursing and physician angst [45]. Those who work in NICUs are at risk for compassion fatigue, moral distress, and burnout [46, 47]. One component of burnout is the depersonalization clinicians cultivate to work in the NICU. Narrative neonatology is one potential solution.

Narrative medicine writing workshops [48] and prompted self-reflection sessions [49], narrative medicine seminars [21, 30, 33], reflections on written stories [50], and storytelling events [40] are all linked to diminishing burnout for attendees. Narrative medicine, as well as other medical humanities offerings [51], can ameliorate the depersonalization which may extend into how clinicians interact with families.

The more exposure we have to narrative medicine, the more we learn to listen, recognize, and honor the plight of everyone in our care – parents, patients, staff, and ourselves. In turn, narrative medicine fosters empathy in the provision of neonatal care [42], and palliative care [52]. Parents, who can benefit from writing exercises while their children receive all types of medical care including neonatal care [53], are literally pleading for more integration of narrative medicine into the NICU so that clinicians may better support them [54].

The benefits of narrative medicine programming can be long-lasting. Narrative medicine activities appear to promote medical trainees’ professional development, including reflection, self-exploration, and awareness of professional identity [55]. Residents who participate in creative writing seminars focused on the craft of writing perceived lasting effects on their powers of observation and provision of empathy [56]. Systematic review of narrative medicine programming highlights relationship building, reflection on perspectives, resilience, increased sense of personal accomplishment, ethical inquiry and narrative competence among the other benefits of this work [57].

**Table 1.** Suggested next readings.

Charon R. The patient-physician relationship. Narrative medicine: a model for empathy, reflection, profession, and trust. <i>JAMA</i> . 2001;286(15):1897–902.
Charon R. Narrative medicine: form, function, and ethics. <i>Ann Intern Med</i> . 2001;134(1):83–7.
DasGupta S. Between stillness and story: lessons of children's illness narratives. <i>Pediatrics</i> . 2007;119(6):e1384–91.
Charon R, Hermann N, Devlin MJ. Close Reading and Creative Writing in Clinical Education: Teaching Attention, Representation, and Affiliation. <i>Acad Med</i> . 2016;91(3):345–50
DasGupta S, Charon R. Personal illness narratives: using reflective writing to teach empathy. <i>Acad Med</i> . 2004;79(4):351–6.

### LIMITATIONS OF NARRATIVE MEDICINE

Narrative neonatology specifically, and narrative medicine more generally, are meant to complement, not replace, the ongoing delivery of medical care. Critics of narrative medicine argue that, when taken too far, narrative medicine can lose sight of the facts inherent in pathophysiology and diagnoses [58]. Not all clinicians are inclined to engage in narrative medicine methods. Narrative medicine does not claim to be an all-purpose solution to navigating the emotional and psychological challenges of the NICU.

More research is needed to understand potential benefits and shortcomings narrative medicine may have in preventing burnout and promoting wellness. Medical research readily skews towards quantitative results. Because the benefits of narrative medicine are qualitative and unexact, studying outcomes of narrative medicine programming is challenging [57]. The long-term impact of narrative medicine interventions on patient care remains unclear and warrant further study.

### NEXT STEPS

Those interested in narrative neonatology may consider narrative medicine seminars or continuing education conferences to gain more understanding about what narrative medicine is and how it is taught. Reading stories of NICU patients, parents, and clinicians is another way to begin the process of broadening clinicians' perspectives. Formal training or individual mentorship to facilitate narrative medicine seminars could be considered for those motivated to integrate this practice in their own NICUs. Table 1 contains suggestions for continued reading about this field.

### CONCLUSION

Narrative neonatology has the potential to promote humanistic care for our patients and families alongside technological care. Clinicians, trainees, nurses, and parents tell each baby's story, lending our own perspectives and truths. These are the narratives of neonatology. Holding space for stories, for neonatal narratives, is to practice mindful neonatal care, to bring humanism to the incubator and to remember, as we peer through the plastic walls at our premature patients, why exactly we chose this work.

*The next morning, you peer through the haze of the humidified incubator and see Kathan sleeping. His ventilator hums. You watch his tongue suckle his breathing tube. For this moment, you marvel at this new person in your care as you fixate on the aimless wiggle of his toes. You unlatch the porthole doors to place your gloved hands into his incubator. He squirms for an instant then settles as you nestle his body. You rest the stethoscope on his chest and listen to the steady pitch of air from his breathing machine. You watch his belly move up and down. Your fingertips sense the gentle resistance of his sticky, immature skin.*

*Satisfied with your exam, you remove your hands from Kathan's home. As you walk away, you consider what story to tell. He is an extremely premature infant whose life was saved by obstetricians. He is a baby whose mother was unconscious for her first child's birth and has yet to see him, touch him, or hear him cry. He is the sickest*

*patient in your care today and the first few hours of his medical management will impact his future. As you walk to speak with his mother, you can think of only one story. He is a boy who is more likely than not to spend months in your intensive care unit and grow up to become a happy teenager [59].*

### DATA AVAILABILITY

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

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#### AUTHOR CONTRIBUTIONS

RF conceptualized this manuscript, wrote the initial draft, compiled all references, and revised the manuscript. RMM conceptualized this manuscript, offered revisions, and reviewed the final manuscript. BSC conceptualized this manuscript, offered revisions, and reviewed the final manuscript. KSG conceptualized this manuscript, offered revisions, and reviewed the final manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

#### COMPETING INTERESTS

The authors declare no competing interests.

#### ETHICS

This story represents a fictional compilation of patients for whom the authors have cared.

#### ADDITIONAL INFORMATION

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