

Creating Space for Narratives in Breakdown to Speak: Death, Liminality and An Ethical Reimagining of Narrative Medicine

By Rachel Reichenbach

Narratives, both within and beyond medicine, are meant to center our existence in the world through the lived experiences we strive to tell. In all their flowery, delicious melodies, and their shattered, incomprehensible chords, the musicality of storytelling—narrative as art—is what privileges narrative as a mode of better understanding our own collective humanity.

This privilege allows fields such as narrative medicine to be particularly powerful not only in fostering mutual understanding and human connection, but in improving the overall quality of healthcare. The doctor-patient relationship is often characterized by an “illusion of communication,” as cultural and experiential barriers create a space in which people speak past one another, without ever listening (Moore and Hallenbeck, 472). Through attending more closely to narrative in their work, healthcare providers can overcome this illusion by understanding the power of narrative as a bridge: as that which helps providers to “cultivate self-awareness in difficult encounters” (475). These narrative medicine-based implementations, particularly in the context of improving end-of-life care, often lean heavily on storytelling as a mode of re-embedding the patient in the social world.

However, now that we find ourselves in a pandemic world—where visitors are limited, hospital rooms are isolated, and the humanity of medical providers is masked by PPE—suddenly our ability to foster connections between the patient and others has become more complicated. As medical providers today seek to reach hundreds of thousands of patients faced with the reality of dying during COVID-19, dying at a distance, dying alone, the need to re-frame the role of narrative medicine is essential.

We are left with the question: What can we do to authentically share space in the storytelling process at the end of a patient’s life, if not physically? What occurs when we strive to implement narrative as a technique in the dying process: a liminal period that defies the very normative structures we have learned to establish our storytelling around? What could be the role of narrative medicine, then, if not to build up structure in such periods of suffering and uncertainty? What would happen if we instead paid closer attention to the breakdown of narrative structure itself—in storytelling, in listening, in understanding?

This essay endeavors to model a more imaginative approach to narrative medicine: one which considers narrative not only in its most sparkling, eloquent form, but also in its authentic breakdown in the dying experience. An examination of several narratives of terminally ill patients, as understood through the critical lens of liminality, will illuminate not only the reality of narrative collapse in terminal illness, but also what might be unearthed in that space of fragmentation. Uncovering the meaning that emerges from within narrative breakdown will both bring to light the unique experiences and needs of dying patients, and ultimately inform a more nuanced understanding of narrative medicine's ethical responsibility.

The Problem with Re-constructing Narratives in De-construction

Scholars have noted a variety of ways in which this narrative breakdown occurs when attempting to illuminate the dying experience. Words do not clarify, but rather further obfuscate lived realities, as “love turns into fear, longing into disgust, sorrow into anger” (Berger and Kroesen 147). This insufficiency of language has often been deemed as that which is precisely the impetus for the breakdown in one's connection to the world in serious illness. Arthur Frank, author of his own memoir of critical illness, describes this phenomenon as it relates to the experience of pain:

We have plenty of words to describe specific pains: sharp, throbbing, piercing, burning, even dull. But these words do not describe the experience of pain. We lack terms to express what it means to live ‘in’ such pain. Unable to express pain, we come to believe that there is nothing to say. Silenced, we become isolated in pain, and the isolation increases the pain. (30)

Not only does the ineffability of dying result in pain for the patient, but it results in pain for the medical provider who, unable to piece together a coherent narrative from a patient, then struggles to empathize, to access the very “common denominator, the transferable currency that does not equate but makes accessible across a divide” that narrative medicine aims to foster (Spiegel and Charon 135).

When one looks to literature, existing analyses of the illness and dying narratives often struggle to create enough space for narrative structure to truly crumble. And understandably so: the characterization of dying in literature faces the dilemma of attempting to describe an experience that exists in a sphere beyond that with which our linguistic pallet is familiar. However, the according discomfort that this uncertainty brings results in two distinct, futile endeavors to externally concretize meaning in the messy narratives of critical illness:

In the first scenario, the sick person is ascribed the responsibility of clarifying their experience for others. Arthur Frank describes how it often falls to the ill not only to “get well but also to express their illness well,” so as to comfort the healthy (Frank 127). Frank describes two children with leukemia who both are moved to act according to what brings peace to outsiders: one who softens the sadness of illness by asserting her empowered presence, who takes off her wig and “widens the circle of public recognition. She has

fulfilled her responsibility,” and a second who tempers the sadness of illness by allowing himself to blend in with the healthy, who “acts according to others’ cues of what they want from him, which is to disappear.” The ethical responsibility to hear, to understand, to connect with the story of the ill person, is shifted onto the sick or dying person themselves—a strange reversal of the intended role of medical providers and scholars informed by narrative medicine.

In the second scenario, observers of the sick person turn to metaphor as a mode of disguising the distressing lack of apt language. Despite the fact that in serious illness, “the incoherence of pain language easily goes wrong,” there seems to be a coinciding understanding on part of the ill person themselves, that “metaphor distorts the experience” (Frank 30). Susan Sontag, in her essay “Illness as Metaphor,” echoes Frank’s experiential knowledge, describing how “the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking. Yet it is hardly possible to take up one’s resistance in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped” (3-4). Metaphor—a tool prolific in narrative medicine’s endeavor to put words to patient experiences—creates a dance of language that conceals and beautifies any slippage of language or narrative structure, at the ironic cost of clouding the dying person’s lived reality. The notion that metaphor could rescue a narrative not only falsely equates a narrative in breakdown with a story that is broken, useless, or incomplete, but also ultimately focuses on the wrong subject: “Quick, prescribe this dying narrative a hefty dose of metaphor!” aims to treat the patient’s story, not the patient.

The use of metaphor in illness narratives highlights the need to move beyond the realization that narratives do in fact fracture in critical illness, and towards a consideration of why artificially constructing this flavor of narrative may be problematic. What reality are we ignoring when we ascribe meaning to the dying patient’s experience with flowery words? What does it mean when someone is at the end of their life—perhaps with hardly even a physical body left to encapsulate their existence—what really, then, does it mean to artificially beautify the very suffering that asserts a dying person’s presence, in their final moments in the world?

When considered in this way, most would understand the problematic nature of forcing a dying person to assume the perspective of the living, to soften the telling of their story (as in the first scenario); or for someone else to take a dying patient’s story out of the context of lived experience and wrap it in metaphor, so as to make the narrative’s ambiguity more palatable (as in the second). In both cases, efforts to re-construct a de-constructed illness narrative not only fail to put words to the ineffable experience of dying, but also unintentionally strip away the autonomy of the patient and their story—precisely the opposite of narrative medicine’s intention.

Beyond the ethically problematic nature of these endeavors to force the fracturing words of a dying person’s story into a neat framework of narrative, as it functions in the normative world of experience, something deeper is also lost in this sort of “translation” of a broken narrative. Within the gaps of a crumbling narrative, within the inconsistencies in language,

tenses, narration even, there exists a purity of storytelling. What if, instead of working to boil down a dying person's words into something the living can understand, we tried to just listen, to follow all the confusing messiness of an illness narrative, to utilize our positionality as medical providers, writers, thinkers in the field of narrative medicine, to simply make space?

In looking to address these questions, this essay now turns to an interpretation of dying as liminal, in order to begin unearthing something within broken illness narratives that holds generative, even imaginative, potential. Ultimately, this analysis seeks answers for how to best treat, serve, and connect with, dying patients and their stories.

The Value in Understanding Dying as a Liminal Experience

For the dying or critically ill storyteller, proximity to death opens up a unique location in which passionately overflowing narratives of experience become interwoven with frustrating moments of ineffability; moments that ignite and transcend the very language they so urgently demand. It is from within this very dynamism that one can understand the dying process as liminal: as an in-between moment, rather than a punctuated, concrete end point. Paul Stenner, in his text *Liminality and Experience* describes liminality as “experience that happens during occasions of significant transition, passage or disruption” (14). Nowadays, perhaps we all understand this notion of liminality a bit more intimately; to live in this moment is to live in the liminal space of a pre-vaccine, pandemic world: between jobs, between scheduled COVID-19 swabs, between barriers of plastic for something as simple as buying a cup of coffee. Our experience in the world is anything but constant, anything but stable. Normative structures of all kinds are fracturing around us, and we, too, often lack the right words to depict all that it is to live in this present moment.

Similarly, the liminal space of death subverts both normative human existence and normative narrative structure. Several scholars have noted this parallel specifically between the death and liminality. Anthropologists Peter Berger and Justin Kroesen offer a valuable take on the liminality of dying as the “ultimate ambiguity.” They describe how “the fundamental ambiguities concerning death—and, as such, life—are not only extremely generative of ideas, practices, and social relationships, but also of paradoxes and contradictions” (1). Understanding death in the context of liminality offers an important lens for understanding narrative in deconstructed spaces. Rethinking illness narratives as narratives of liminality pushes back against equating such transition periods with stagnancy or degeneration. While the physical body might degenerate in the dying process, the experience of dying itself can be understood as a powerful, generative process: a liminal period that makes space for new understanding, simply by existing beyond the constructs that dictate how society typically functions.

When examined closely, one can understand narratives of critical illness not only as stories that are falling apart, but as stories that expose creative space in their very fissuring. Returning to our understanding of death as liminal, this notion resonates with Victor Turner's observation that “liminality need not be free of structure” (Stenner 164). He relates

liminality to something he calls “communitas,” which “describes the kind of bonds in liminal periods that are undifferentiated, where humans can meet as humans, outside of prescribed social roles and as equals, and jointly experience their co-humanness,” a reminiscent echoing of the dynamics that narrative medicine aims to create between medical providers and patients. It is from within this more fundamental interaction in the world and with others that liminality and “communitas” serve to be “the creative fountains of humanity when normal structures and rules are suspended,” something he terms “antistructure.” The potential utility of narrative medicine lies in its ability not only to create structure, but to invite in, to listen to, to make space for, the breakdown within narratives of critical illness and death—and to see what emerges. In this context, “antistructure” might be understood as that which precipitates when narrative medicine is harnessed as a tool to allow fracturing illness narratives the space to speak.

The Generative Potential in Fracturing Narratives of Terminal Illness

In narrative analyses of dying patients’ stories, depictions of the dying person often over-construct meaning and oversimplify experience, doing so at the expense of the patient’s agency. This phenomenon—largely a result of the ironic duality of one’s desire to understand, but inability to grasp, stories in such raw breakdown—belittles the patient to someone who is simply “being colonized as medical territory and becoming spectator to [his/her/their] own drama” (Frank 56). The dying patient’s story is spoken over when medical providers, writers, and even family members, unknowingly ascribe pity to the dying person, and then interpret that pity as a monolithic side effect of becoming ill. This proscriptive and reductive framing of illness blankets both illness narratives, and the patients who share them, in a milieu of sadness and helplessness: a strange sort of positive feedback loop, in which an externally located interpretation of death as sad is pinned to the dying person.

The following analysis aims to exemplify a more nuanced attention to illness narratives in breakdown, endeavoring not to construct, but rather to allow the messiness of stories in the space of death to speak for themselves. Resisting the impulse to equate the typically unavoidable feeling of “aleness” in illness, with feelings of despair or powerlessness, this section will look to narratives of terminal illness in order to unearth that which is positive, generative: the “antistructure” existing within the liminal space that we refer to as “dying.” Ultimately, if we can reconsider illness narratives in this way, we might also find a way to hear and reframe the stories of dying patients, thus offering a framework for better understanding how to care for patients dying in the solitude of the COVID-19 era.

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In *Spy of the First Person*, author Sam Shepard creatively chronicles his own journey dying from ALS, in a stream of consciousness narrative that intentionally conflates the first and third person. Constantly weaving between speakers with different points of view, Shepard writes as if he is watching a hologram movie of himself. The narration of the book shifts between the version of Shepard who is watching, and the version of Shepard who is being

watched. For Shepard, the most authentic telling of his experience of dying from a degenerative illness is to describe the present, liminal moment, as alone, yet not lonely: “the experience of the present is one of anonymity. Complete anonymity. The way the sun hits the pavement. The way it hits your bare feet...the way your eyes open underwater and see things. What do you see? You see other people, other human beings struggling to keep their eyes open underwater” (49). Shepard offers a profound rethinking of anonymity and aloneness in the present moment, not only as that which is fundamentally human, but as something that connects us with others.

Shepard’s present experience always manifests as an extension beyond himself and into the world. He describes how “somebody is turning off a lawn mower. Somebody’s sitting at a bus stop. Somebody’s waiting for somebody...somebody’s waiting” (10). Rather than specific names or descriptions, he describes all people simply as “somebody,” and thus his commentary makes clear the shared aloneness of every being he watches—including himself. Illness seems to open his eyes to the anonymity of his own life, something as commonly shared with others as the banal, everyday experience of turning off a lawn mower or waiting at a bus stop. For Shepard, while anonymity might be intensely, personally experienced, it is far from a unique experience. His free-form, deconstructed story most certainly reflects the strange challenge of learning how to die, which terminal illness does of course bring. However, rather than depicting this process as passive or sad, Shepard takes the reader on his journey through understanding how dying opens up a space for questioning, for considering one’s connection to other people: a generative, liminal space.

While illness has the power to clarify creative potential within the dying process for the ill person, this often is not the case for the medical provider. This difference in ability to grasp the potential within the dying experience reflects a difference in relative experiences of time. As Shepard describes, “the present is a many-faceted thing. Much like the past” (49). Every person’s relationship to the present moment is defined by a variety of factors, including the relative clarity of one’s proximity to death. As such, how the dying patient and how the medical provider perceive the unfolding of time is bound to be inherently different.

Shepard’s work also reveals one potential medium for clarifying and traversing these differences in the perception of time: narrative. Narrative itself is no stranger to the function of time in dictating meaning. Rita Charon even notes that “when we human beings want to understand or describe singular people in particular situations that unfold over time, we reach naturally for narrative” (vii). A traditionally written narrative arcs in time from beginning to end; the observer simply a spectator to the passage of time in their own life. However, the way in which time unfolds in the liminal experience of illness necessarily breaks down and transcends traditional narrative and literary structures. The dying person does not experience time in terms of concrete start or end points, but rather as a period of in-betweenness, of liminality.

Understanding this differential experience of time illuminates the importance of preserving the agency of a speaker’s voice by reading an illness narrative in its deconstruction, rather than pinning meaning upon a story from the perspective of the listener. Returning to

Shepard's writing, even his loose literary form depicts a sort of floating through the world in rigid opposition to the normative structure of time. He recognizes the difference in his perception of time as a dying man, noting how "nobody hangs on [others] words. Nobody hangs in the moment. Nobody really hangs for nobody" (50). Shepard notes how the people around him move through the world so quickly, defined only by the starts and the ends, as if living frantically were the key to escaping the anxiety of aloneness.

Shepard's self-aware understanding of the temporal atmosphere of dying uniquely makes space for a generative, creative narrative of liminality. His repetition of "nobody," characterizes not only aloneness, but also a sort of disbelief in how the people around him seem to view time so differently—the sort of muted epiphany that becomes possible within the liminality of death. In Shepard's recognition of the inability of the people around him to pause, to slow down, he is not filled with loneliness, but instead is moved to study each detail of every moment. His entire narrative—fractured and cracking in structure, form, and syntax—reflects his understanding of the power of anonymity to teach a dying person how to live in a world of possibility, despite carrying an intimately concrete understanding of mortality.

The opposite temporal perspective, that of outsiders observing the dying person, is explored in Susan Sontag's short story, "The Way We Live Now." In a fracturing narrative form that moves in and out of focus—without regard for quotations, or even indentations, to distinguish each speaker—the story of a man dying from AIDS is told exclusively from the perspective of his friends and family. Friends describe their fear of getting too close to the sadness of the sick: "walking through the hospital averting their eyes from the other patients sunk in their beds, with tubes in their noses, irradiated by the bluish light from the television sets, the thing I can't bear to think about, Tanya said to Lewis, is someone dying with the TV on." They fear the idea of someone dying so alone that only projections of people, people on a television, might bear witness to their death; at once completely anonymous, yet surrounded by a world of millions of unreachable people – an infinite separation established by a single screen. In the same breath, Tanya and Lewis fear even making eye contact or acknowledging the existence of the dying patients—in and of themselves contributing to the very dehumanizing loneliness and sadness they fear.

For Tanya and Lewis, time unfolds in a non-liminal space; the structures they are familiar with are not in breakdown, and they lack the ability to understand the dying process as anything beyond their learned responses of fear and sadness. In their inflexible understanding of temporality, and their desperate efforts to disguise the sadness and isolation that they themselves dread, the living fail to understand the space of possibility, of agency, in the dying process. Yet this experience is not unique; what medical providers, families, and friends often forget when watching their loved ones die, is that their perspective as viewers—shaped by a non-liminal present and normative experience of time—is inherently myopic; it does not hold a monopoly on the mood of the experience of dying. Observers fail to remember that the dying patient, described through a different temporal lens, is also a living patient.

This duality is made clear simply in the entirely external storytelling within “The Way We Live Now,” which illustrates the dying experience without ever giving a direct voice to those who are actually experiencing the dying. However, the so-called man dying from AIDS speaks loudly in his absence of a voice in the narrative. The reader never actually hears what the patient feels, or what the patient thinks of his solitude (or perhaps, what the patient thinks of this intense, almost terrifying sadness to which he has been ascribed). Perhaps the man dying from AIDS shares the understanding in death that Shepard does: that the experience of dying holds a generative, illuminating potential—an antistructure. Perhaps he too feels the miraculous quality of hopefulness within the journey of learning to die, that, for Shepard, becomes strangely palatable in its bizarre ability to illuminate truths about life and existence that simply cannot be represented in the confines of structured, normative language.

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By examining these narratives of critical illness in all their chaotic fracturing—of rapidly changing tenses and perspectives, of voices heard in their very absence—the association between sadness and dying reveals itself as little more than a precipitate of the living observer’s outside perspective. Indeed, the experience of dying can be, in part, a sad one. However, perhaps this sadness is the result of dying folks’ inability to share the incredible antistructure that liminal existence has afforded them: new possibilities, new perspectives on understanding life. Despite how connected the dying person might have been to various individuals through life, sharing across temporal lenses, sharing between liminal and non-liminal spaces, can be incredibly challenging.

And yet, we see how narrative uniquely offers a starting place for re-connecting these worlds of experience. The dying process entails far more than simply a sorrowful, final stop in the journey of life; terminal illness narratives teach us that even dying has the power to be an imaginative and liberating journey. If we as outsiders actively choose to stop pouring the stories we hear through the filter of our own experience of time, then we too have the potential to understand the stories of the dying as far more than pitiful epitaphs. As medical providers specifically, perhaps the best we can do to support a dying patient is to honor the reality of their narratives in de-construction by refusing to pin down their experience in our words.

It must be the responsibility of the listener to not only attend to narrative, but to note when narrative structures breakdown; to listen to the cracks and gaps in the storytelling of dying patients; to unearth what is generative in the liminal space of death, so as to reach a place of empathy. This re-imagined narrative medicine argues a hopeful point: even if a patient is dying in isolation, or in the socially distant world of COVID-19, that human being need not die at a distance from meaning or connection—if only we allow their story the space to manifest, in all its glorious fracturing.

The Ethical Implications of a Re-Envisioned Narrative Medicine

Through uncovering the generative potential of disintegrating narratives in the liminality of death, this essay aims to offer a foundation for better serving dying patients, and for reimagining narrative medicine's utility. Ultimately, this work seeks to offer a starting place for how scholars and medical workers might engage with narrative medicine differently, in order to approach compassionate, ethical medical care not only during this pandemic, but moving forward as well.

Understanding terminal illness narratives as liminal not only aids medical providers in caring for dying patients, but also provides a new set of tools for questioning current paradigms of power within medical delivery more broadly. When one characterizes the experience of dying as liminal, dying inherently occupies a space in which “the forms of process (socio-psycho-organico-physical) that usually sustain, enable and compose our lives are, for some reason, disrupted, interrupted, transformed or suspended” (Stenner 14). This breakdown allows one to separately examine each of these “forms of process” that sustain ordinary life—not only those within a dying physical body, but also the social and political structures in which those bodies inhabit. Exploring narratives in breakdown, and thus normative structures in breakdown, reveals these normative structures for what they are, and in particular, for whose voices they silence.

As the world struggles to provide medical care and palliative support for hundreds of thousands of people dying from COVID-19, we, as practitioners of narrative medicine, must also be willing to make space for the stories of patients who continue to fight their way through a medical system not designed for them. Statistics reveal the insufficiency of basic medical care for many patients, and not only for those who lack access to affordable healthcare. Virtually all providers would agree that the color of one's skin and one's gender identity should never dictate the quality of medical care received; and yet, statistics indicate a very different reality. Numbers may bring certain medical injustices to light, but numbers offer no magical solution in and of themselves. Statistics can too quickly become the tools of power structures, little more than boiled down, impersonal abstractions of lived experience, reconstituted only to be discussed or even debated. Patients, individuals, *humans*, cannot be simplified to corporeal manifestations of “racial disparities in health,” or “sexual and gender minority health inequities.” Studying statistics in isolation, severed from the lived experiences that created them, is a form of silencing, a form of violence.”

In the past, narrative medicine has answered this inadequacy of statistics with a re-centering of patient stories, a practice revered for bettering patient care. However, this moment in the world calls for a more nuanced response, for a reimagined narrative medicine. Simply the commitment to value stories over statistics is not enough. Narrativizations of experience are useful only insofar as they achieve critical self-reflection. For providers, fostering a greater awareness of the lived identities one does, and does not, possess, is key to better informing one's narrative medicine implementations. We need to listen to stories, yes, but we must also interrogate how our own lens skews and warps our perception—and often in narrative medicine, our retelling —of the stories we hear.

Addressing current public health crises begins with challenging our role in creating them, even if, perhaps especially if, that requires us to reflect upon where our well-intended narrative interventions have gone awry. As J. Hillis Miller writes, “ethics itself has a peculiar relation to that form of language we call narrative” (40). As explored in both *Spy of the First Person*, and “The Way We Live Now,” there is a need to acknowledge whose perspective, and whose voice, is being privileged in the telling of a story. The inherently ethical role of language, particularly in narrative, demands a responsibility to not only listen to who is speaking, but to address the inherent biases the listener brings—and consequently, to address who is being spoken over.

To engage with a reimagined narrative medicine is not only to critically engage with narrative, but to do so with clear ethical intention. Patient narratives heard by medical providers in this moment—stories that speak to a deadly virus, to racism and racial injustice, to ongoing human rights violations of all kinds—do more than speak to a world on fire; these stories demand that something different be born of the ashes. They implore medical providers and scholars of narrative medicine to not speak over narratives in breakdown, but rather to hear them in their very fragmentation, to give them space to manifest the ineffability of suffering. And they ask that we bring the same intensity to saving lives that a global pandemic spurred, when addressing the urgent medical inequities that we all must collectively face moving forward—for a vaccine will never replace the need for more ethical responsibility in medicine. Not only hearing, but addressing, these demands is both the power and the responsibility of a re-envisioned narrative medicine.

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Rachel Reichenbach (she/her) is a community organizer and scholar whose interests lie at the intersections of narrative theory and applied ethics. A Stanford University graduate in Comparative Literature, Reichenbach utilized her honors thesis, "The Ethics of International Community Service: Narrative, Philosophy, and Education as Solutions," to create the theoretical foundation for her recent, praxis-focused research project in Vietnam, as a Fulbright Scholar. An incoming medical student at the University of Arizona School of Medicine - Phoenix, she intends to help reform and reimagine healthcare ethics, and is particularly committed to creating space for queer and trans patients who continue to be systematically excluded from and made vulnerable by the healthcare system as it stands.

