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Illness narratives: reliability, authenticity and the empathic witness



Johanna Shapiro

EDITOR'S CHOICE

Several scholarly trends, such as narrative medicine, patient-centered and relationship-centered care, have long advocated for the value of the patient's voice in the practice of medicine. As theories of textual analysis are applied to the understanding of stories of illness, doctors and scholars have the opportunity to develop more nuanced and multifaceted appreciation for these accounts. We realize, for example, that a patient's story is rarely "just a story," but is rather the conscious and unconscious representation and performance of intricate personal motives and dominant meta-narrative influences. Overall, this complexifying of narrative is beneficial as it reduces readers' and listeners' naïve assumptions about reliability and authenticity. However, the growing body of scholarship contesting various aspects of personal narratives may have the unintended effect of de-legitimizing the patient's voice because of concerns regarding its trustworthiness. Further, the academy's recent focus on transgressive, boundary-violating counter-narratives, while meant to right the balance of what constitutes acceptable, even valuable stories in medicine, may inadvertently trivialize more conventional, conformist stories as inauthentic. While acknowledging the not inconsiderable pitfalls awaiting the interpreter of illness narratives, I argue that ultimately, physicians and scholars should approach patient stories with an attitude of narrative humility, despite inevitable limits on reliability and authenticity. While critical inquiry is an essential part of both good clinical practice and scholarship, first and foremost both types of professionals should respect that patients tell the stories they need to tell.

In the post-Flexnerian era, physicians increasingly viewed the patient's story with a certain scepticism and discomfort because of its subjectivity and perceived unreliability. Instead, they came to depend more on impartial clinical data obtained from various technical manipulations of the Foucauldian clinical gaze (CT scans and MRI imagery, lab values, stress tests, etc), as well as on their own positivist scientific expertise. Various scholarly trends have reintroduced the importance of the patient's story to the field of medicine. The thrust of narrative medicine scholarship, for example, has been to move the patient's voice from a position of relative marginalisation to one reinvested with a measure of authority.^{1 2} This scholarly development complemented the call for patient-centred³ and relationship-centred⁴ care, both of which reinstate the value of the patient's story in caring for patients.

However, despite these movements, as Sayantani DasGupta points out, for

a variety of both medical and literary reasons, patients' stories are still at risk of being perceived as untrustworthy, inaccurate, dishonest or mistaken.⁵ 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. In service of a very different agenda, literary scholars and narrative ethicists have also complicated the way we interpret narratives of illness by engaging with questions of authenticity, integrity and believability. Indeed, the very term unreliable narrator refers to someone who, either out of self-interest or ignorance, tells a tale that is biased, misguided or deceptive.⁶ Awareness of the limitations of the teller can add salutary nuance by repositioning our understanding in a more sophisticated and critical manner, but can also threaten attitudes of respect and trust for the patient's voice. The crucial question is how best to consider issues of reliability, trustworthiness and authenticity within the context of both clinical medicine and literary theory.

UNRELIABILITY AND INAUTHENTICITY IN FIRST PERSON NARRATIVES

Questioning narrative fundamentalism and reliability

In her analysis of a 2003 reissue of Lucy Grealy's classic story of illness, *Autobiography of a Face*, including a tell-all 'Afterword' by her friend, sometime care giver, and fellow writer Ann Patchett, Rebecca Garden tackles the question of narrator authenticity in illness narratives, particularly as conveyed in the first person voice.⁷ She makes the important point that the readers of such narratives, whether they are physicians trying to educate themselves about the patient experience, or other patients attempting to make sense of their own encounter with illness, tend to assume that these accounts represent objective truth—'what really happened'. Just as the ideology of science privileges the voice of the expert, this ideology of personal experience enhances the authority of the person who underwent the event firsthand. Yet such narrative fundamentalism, in which the reader/listener unquestioningly takes the patient's account at face value, is a simplistic view of the nature of story. Even in the 'I was there' narrative, there is never a literal recounting of all events exactly as they occurred.

The bias of personal motivation

As Garden and other literary scholars remind us, all narratives are shaped, or 'constructed'; all narratives are the results of authorial decisions, made for a variety of aesthetic and personal motives: coherence, relevance, self-presentation, correcting earlier histories, monetary gain, even 'payback'. As Chambers once noted tellingly, 'Stories are not innocent'.⁸ Hardwig contends that autobiographies are 'both epistemically and morally suspect', containing mistakes, omissions, distortions and blatant lies.⁹ He asserts that most people are chronically self-deceiving beings whose self-presentations lack transparency and honesty. Paley notes that in first person stories we are likely to portray ourselves as kinder, cleverer, funnier and more successful than we really are. We may ignore certain facts and exaggerate others to win sympathy, invite admiration or minimise responsibility for mistakes and wrongdoing.¹⁰ First person narratives have also been criticised as confessional, solipsistic and unconcerned with larger social issues.¹¹

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The influence of meta-narratives

Further, beyond conscious or unconscious personal choices in writing or telling, all narratives are themselves necessarily influenced by persuasive, at times coercive, external forces embedded in established power structures engaged in active ideology-making.¹² People do not simply pull their narratives out of the blue, but in fact are deeply constrained by the power of the dominant narrative conventions and meta-narratives that are most readily available to them as a result of their particular place in time, history, culture and society. Paley contended that most meta-plots, such as the conviction of a 'just world', lead to the reflexive reconfiguring of bad situations as events that are actually beneficial, positive and educational or spiritually illuminating, if only we could understand them fully, because such interpretations support the status quo.

Other scholars have observed that 'feel-good' stories that stimulate satisfaction, pleasure or admiration are easily believable to the emotionally susceptible reader or listener, but this does not make them either accurate or true.¹³ This means that family members, friends and physicians may reflexively favour or approve certain kinds of patient stories over others, although these preferred stories may not feel genuine to the patient telling them. For example, patient narratives of conformity, optimism, acceptance, cooperativeness and positivity reinforce physicians' view of themselves as competent, effective and benevolent professionals.¹⁴

Limitations of recovery and quest meta-narratives

The meta-narrative of most concern to Garden (based in part on the work of Arthur Frank¹⁵) is that of the comic plot, which in Aristotelian terms refers to a happy outcome that befalls a rather ordinary, but sympathetic character. Often this takes the form of a U-shape, in which the action begins in prosperity, descends into potentially tragic events and rises to a happy conclusion.¹⁶ In the domain of illness stories, the comic plot produces the recovery narrative (what Frank calls the restitution narrative). Briefly, this narrative adheres to the following structure: patient gets sick; patient receives medical intervention; patient recovers and returns to pre-illness life.

Another twist of the comic plot that Frank dubs a quest narrative contains the necessity for the protagonist to somehow

be better off at the end of the story than at the beginning. In illness narratives, this requirement can include not only being cured, but also becoming wiser, more spiritual, having a greater appreciation for what 'really matters', developing deeper, more satisfying relationships with family and friends and so forth. Such narrative structures can easily be seen as reflecting the 'just world' hypothesis,¹⁷ presenting a Panglossian panegyric that everything, even a devastating medical condition or terminal illness, is for the best in this best of all possible worlds. The well-placed concern of many scholars is that the narrative constraints of both the recovery and the quest meta-narratives prevent other patient voices from emerging, ones that, for example, express anger, despair, suffering, failure or protest, or admit the lack of easy narrative resolution, especially where chronic illness and disability are in play.

The operation and influence of both personal motivational bias and existing meta-narratives are crucial qualifications to our understanding of patient narratives because otherwise it appears as though people are 'just telling their stories'. In fact, they may be telling stories that they feel motivated to tell in order to be perceived as 'good' patients or commendable individuals; or they may end up availing themselves of idealised, culturally accessible plots that represent how things should be (a kind of societal wish fulfilment) as opposed to how they actually perceive things to be.¹⁸

THE UNRELIABILITY OF THIRD PARTY REPRESENTATIONS

If there are so many risks in first person accounts, perhaps after all patients should let other people tell their stories for them, especially trusted people such as significant others or even their physicians. However, third party representations of others are not inherently more reliable or objective than autobiographical writing. They too are driven by the motives, perceptions and values of the teller, all of which may have strong elements of subjectivity and bias. For example, a third party may have a personal motive for telling a story a certain way; or may have a perspective limited by training¹⁹; or may have values that impel them to make a certain point in the presentation of another's story. The clinical presentation, for example, tells the story of the patient according to an objective formula, but has obvious limits imposed by its structure and differential diagnostic emphasis. Even the patient chart note, often criticised by humanities scholars for its reductive

formulation,²⁰ does not contain 'just the facts', being itself a distillation and interpretation of what is pertinent in the physician's view regarding the patient's chief complaint.²¹

Although Garden's article raises questions about the 'truth' of the first person authorial voice, it expresses equal if not greater concerns about the appropriation of one's story by another, particularly when the original story belongs to someone who is a 'vulnerable subject',²² individuals who by virtue of being unable to speak for themselves, too sick to speak for themselves or being dead lack the capacity to at least offer counter-narratives. In her article, Garden focuses on how Patchett's tell-all approach to Grealy's life complicates the version of self that Grealy presents, but is not necessarily more trustworthy than Grealy's portrayal.

Others have raised similar concerns about the 'borrowing' of other's stories, particularly in the medical context, where a growing number of by definition powerful physicians are choosing to recount their patients' stories (or at least their perceptions of their patients' stories). Physician-authors such as Jay Baruch unequivocally prioritise patient care over narrative;²³ and others caution that the risks of physician storytelling include violation of patient privacy and exploitation of others' suffering for material gain.²⁴ Charon has laid out elaborate (and some²⁵ would argue impractical) guidelines²⁶ for not carelessly appropriating the stories of those with whom one has established a moral and relational professional obligation to serve. Garden writes that the most important question to ask in evaluating the validity of such third person writing is, who benefits from the telling? She implies that scepticism should be an equal opportunity component of critical thinking meriting application to all texts regardless of the perspective of the source.

ARE UNRULY NARRATIVES MORE RELIABLE/AUTHENTIC THAN CONVENTIONAL ONES?

The allure of the transgressive

The academy has performed an invaluable service for clinicians by enabling them to see that many kinds of stories exist, and that many of these are uncomfortable to listen to, in particular stories of disregarded patients, such as those addicted to drugs or alcohol,²⁷ suffering from contested illnesses²⁸ or who are obese.²⁹ Physicians sometimes bring a devaluing attitude to these patients' narratives

(‘He’s drug-seeking’, ‘No evidence of organic disease’, ‘She says she only eats lettuce’); and literary scholars and narrative ethicists have gone a long way towards rehabilitating such stories. Nevertheless, out of a desire to bring these counternarratives into the light of day, scholars may have enthroned stories of ‘contestation and opposition’ as more authentic than those that are conforming or restitutive.

Within the academy, transgressive, boundary-violating, defiant counternarratives are championed precisely because they adopt a gritty outsider position, which has an implication of greater authenticity.^{30–31} But it is also true that stories of transcendence and joy can have a transgressive dimension. Just as it is hard for some to accept that persons with disabilities would not necessarily want to ‘change’ into persons without disabilities (cf. deaf culture), it may be difficult for a healthy person to understand that there can indeed be meaningful, even transformative aspects of experiencing life-threatening illness. Such accounts may indeed conform to the conventional comic plot, but at the same time, they also may be offered in a spirit that violates the carefully maintained modernist dichotomies of health/illness, good/bad. Contestation and opposition do not automatically constitute more valid criteria for ‘truth’, reliability, authenticity or trustworthiness than other authorial stances. A brutal, unremittingly ugly narrative is not necessarily a more ‘real’ narrative than a transformative one.

Even when a comic or quest narrative is not transgressive, it should not be automatically disqualified as inauthentic. It has been pointed out, for instance, that there is something of the chaos narrative in most stories of illness,¹⁵ with the implication that such stories should necessarily display some elements of incoherence. But narrative coherence and smoothing per se should not necessarily be a red flag for concerns about fakery or speciousness. If the author has found meaning in faith, for example, this in and of itself should not result in trivialising the story simply because it expresses what in some parts of the world is a dominant, culturally normative view. If the author has come to peace with her illness—at least in the story offered—this does not necessarily represent a simplistic resolution masking ‘more authentic’ despair and desolation. While it is unquestionably true that sometimes the patient’s level of chaos, panic and distress cannot be incor-

porated into a heroic storyline,³² it is also true that some stories are, indeed, heroic, if only on a small scale. It is valid to assert that a narrative in which loss is progressively transformed into restored wholeness³³ is indeed a conventional narrative. But for some it may speak their truth. Joanne Banks once wisely wrote that ‘It is possible to pass through tragedy to a serene acceptance of life’s integrity’.³⁴

Approaching all stories from a context of narrative humility

In the face of inevitable narrative unreliability in first person, third person, transgressive and conventional accounts, how should physicians and scholars interpret the stories of illness that are written down in books and blogs, or that are told daily in exam rooms? One suggestion has been to pursue multiple accounts representing divergent perspectives in order to develop a more nuanced and refined grasp of the other.³⁵ But in patient care—and even in literature (the Grealy/Patchett example being a fascinating exception)—this is usually not feasible. When it is not, the first person voice, no matter how incomplete, flawed, transgressive or unexceptional, still merits respect and empathy because ultimately it belongs to the patient and represents the patient’s truth in that specific iteration.

The agency of the teller

Although patients are influenced and often limited by the prevalent narrative conventions available to them, as well as by the often oppressive power of dominant narratives, it is possible to attribute greater agency to the tellers of stories than these postmodernist critiques allow. In other words, patients often make aware and conscious choices about the stories they choose to tell based not only on external societal pressures but also on their own desires and intentions. For example, transformative stories can be an empowered choice on the part of the patient that may at times *align with but are not wholly determined by* the dominant cultural or societal narrative, and are chosen for reasons not exclusively of subjugation and control, but also of personal liberation. Stories can act as sites of oppression, self-delusion and dissimulation to be sure, but they can also serve as acts of self-empowerment.³⁶ A story of wisdom gained, of possibility and love, may be the legacy a patient with ovarian cancer wants to leave her children, although it does not represent the entirety of her illness—and life—experience.

A proper balance

Within the parameters of critical analysis, we must allow for stories that are valuable to the teller,³⁷ whether they take a transgressive or a transformative turn. Because the story of the thing is never the thing itself, we must be sure to ask, what forces are at play that might influence the narrator in *any* direction, whether boundary-violating or boundary-conforming? Are there cracks in the smooth surface of one patient’s narrative, where other more unruly narratives should be explored? Conversely, is there a desire to dramatise the chaos, with the goal of heightening interest in an otherwise too-bland story, that needs to be examined? The point is that it is easy to develop intellectual and philosophical blinders so that scholars and clinicians alike end up making uninterrogated assumptions about concepts such as coherence, unruliness, conformity and transformation that may distort the patient’s desire and intention.

Patients’ narratives themselves are not simplistically one thing or another—not entirely an act of rebellion against confining prevailing norms, nor an exercise in crafting a positive image for posterity. All stories necessarily contain elements of both authenticity and inauthenticity, are always partly trustworthy and partly untrustworthy, to some degree are unavoidably self-representations and performances. However, as consumers and necessarily evaluators of narrative, the unconscious biases and predilections of clinicians and scholars, whether in one direction or another, may diminish their capacity to complicate and fully appreciate the stories they hear and read. In the analysis and interpretation of narrative, moving beyond morally superior dichotomies of authentic/inauthentic, true/invalid, right/wrong³⁸ will enable both groups of professionals to explore the less definitive position that much about values, personal motivations and worldviews can always be discovered in the way people frame stories of their own experiences.³⁹

Narrative humility

Bringing a critical mind to narrative is indisputably important in order for us to learn the lessons the author intended, as well as the lessons the author perhaps did not intend. But such critical thinking should occur within a compassionate and humble context, in the felicitous phrase of DasGupta, a position of narrative humility⁴⁰ that acknowledges that patients’ tellings are not objects to be

comprehended or mastered, but rather dynamic entities that we approach and engage with, while simultaneously remaining open to their ambiguity and contradiction. Such an attitude admits the possibility that self-representation is not entirely driven by motives of placating or pleasing others, conforming to prevailing norms or being well-regarded ('illness brightsiding'⁴¹). It reminds clinicians and scholars alike that patient narratives may also be guided by a desire to make meaning out of suffering,⁴² connect with one's highest personal aspirations or with an eye to one's legacy with family and loved ones, and that regardless of what drives the story, it remains the story the patient wanted to tell.

An old folk proverb asks, 'What is truer than the truth?' The answer? 'A good story'. For patients facing serious illness, telling their stories is one of the few aspects of their lives that remains somewhat under their control. Are these 'true' stories? Almost certainly not, at least not in the sense of being truer more reliable, or more authentic than other stories—even than other stories the patients may decide to tell at other points in time (eg, compare Leonard Kriegel's early understanding of the personal impact of polio on themes of self and manhood in *A Long Walk Home* with his later views as expressed in *Flying Solo: Reimagining Manhood, Courage, and Loss*).⁴³ But, at least, for the patients, these can be 'good stories' in the sense that they are shaped in the way the patient wants, and convey the meaning and significance that the patient intends to convey.⁴⁴ From this perspective, the storyteller should be granted the privilege of poetic licence,⁴⁵ which trades accuracy and precision for personal meaning.

Every narrative is a negotiation about what reality is really like. When physicians and scholars turn their attention to illness narrative, there must be appreciation and regard for the patient's choosing to tell that particular version of that particular story at that particular point in time. Ultimately, the patient's story belongs to the patient, not to the physician and not to the literary scholar, and needs to be approached with humility, respect and honouring,⁴⁶ as well as mastery and critique. Frank introduced the concept of 'thinking with' in contrast to 'thinking about' stories,⁴⁷ a form of empathic witnessing that enters into narratives rather than dissects them. This does not have to be the end of scholarship, but it must be the context that drives critical analysis and interpretation.

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Poem

The Lady in Pink

From the cancer patient to the surgeon
By Rachel Brown

There was a young lady who said
As she lay—quite exposed—in a bed
“When poking around
I think that I’ve found
A lump that has filled me with dread”

So they kneaded and massaged and squeezed
And sampled a smidgeon to freeze
And he told her quite straight
That her cancer was late
But he’d cut it all out—if she pleased.

Then she said to the surgical team
“I think that your plans are extreme
Though you may be the best
You are only the guest
Of boobs owned and grown by a queen.”

But when he had done what they do
She found that her outlook was new
When her breast disappeared
Her foot reappeared
She’d a vertical view of her shoe

And she thought—now he’d done with his knife—
She was going to get on with her life
She said to herself,
“I am not on the shelf
And my girls have always looked nice”

Then said the young lady in pink,
“The results of mastectomy stink
Though my tits are pits
I just love them to bits
Can you give them a tweak, do you think?”

For Alison and Martha, and all those women who face cancer with courage and style.

Rachel Margaret Anne Brown

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