

storytelling in medicine

*Tell a story of a story
From zero hour to 12 AM
From the good to the bad,
Tell a tale, save my life
A life I want to have
Speak for me, Scherezade*

*Dipesh Navsaria
10 May 2004
(revised 14 March 2006)*

Storytelling has a variety of uses in medicine, particularly in the realm of medical education. Given how medicine views itself as an objective, rational science, it may seem an odd venue for storytelling, a craft grounded in fiction, emotion, and folklore. However, the fact of the matter is that medicine does deal with humans on both the patient and provider sides of the equation, and humans are storytelling beings.

In exploring this subject, I'd like to begin by discussing the *need* for storytelling in medicine and how it fits into the fundamental principles of medical interactions. Next, we'll explore the possible uses of storytelling in three different but interrelated venues: medical education (i.e. in teaching health care providers), interprofessional interactions (working with other health care professionals to share ideas and knowledge), and, finally, patient-provider interactions.

*"Te, the tale * save my life—
The Need for Storyte, ing in Medicine*

One could fairly argue that a focus on a subject as seemingly arcane as storytelling in medicine is ridiculous, given the issues that besiege medicine

* The cover and section epigraphs are from the soundtrack to *Zero Patience*, a 1993 John Greyson movie musical about HIV/AIDS which deftly weaves story in and out of the world of medicine and AIDS; many references to storytelling are made.

on all sides: costs, work hours, reimbursements, the uninsured, malpractice, and many others. Is storytelling solely an indulgence for literary-minded doctors? In an evidence-based field, shouldn't we be asking if storytelling will improve quality of care?

We should. Many years ago, in response to the growing influence of technology in medicine, the fundamental principle of exploring and analyzing a patient's illness in a biomedical framework was altered to include the mental and contextual aspects as well: the biopsychosocial model was born.¹ This model has become the fundamental principle of viewing illness in modern medicine.

In order to evaluate the patient as an individual person, there are no formal tests or studies possible. What there is, however, is the story of the patient's experience with illness. In order to understand and relate to this important facet, health care providers must understand what it means to tell a story.* By developing a capacity to parse a patient's story, health care providers will not only develop a rapport, they will understand at a deeper level what their patient desires from the encounter: knowledge, cure, palliation, reassurance or whatever. Effective treatment requires effective listening. This allows for increased quality of care, decreased use of

1 Engel GL. The need for a new medical model. *Science*, 1977, 196: 129-136

* Or, if the term "storytelling" evokes too many images of "lap time" at the local public library, the fancier term "narrative medicine" can be used.

expensive technology, and, of course, decreased malpractice claims.

This is not to imply that it is all a one-sided understanding of story; patients themselves often come with expectations that medical encounters will be driven almost wholly by technology. By creating an environment where story is not only encountered but respected and given primacy of place, the expectation will be focused back on the patient and their issue rather than on the by-products of technological determinism.*

There is organized professional support for improvement in communication in medical encounters. The 1999 Bayer-Fetzer Conference on Physician–Patient Communication in Medical Education promulgated a document called “Essential Elements of Communication in Medical Encounters”, also known as “The Kalamazoo Consensus Statement”.² The following essential sets of communications tasks were laid out:

1. build the doctor–patient relationship
2. open the discussion
3. gather information
4. understand the patient’s perspective
5. share information
6. reach agreement on problems and plans
7. provide closure

Storytelling and an appreciation for story can easily become an integral part of the first four tasks, and support the remaining three.

* See, I did listen during LIS390 lectures.

2 Bayer Institute for Health Care Communication. Essential elements of communication in medical encounters: the Kalamazoo consensus statement. *Academic Medicine*, 2001, 76: 390–393

The study of narrative based medicine has been gaining ground over the last decades, and many articles have been written on it. In a notable series regarding narrative based medicine for the British Medical Journal, Greenhalgh and Hurwitz make the following key points from their initial article:

The processes of getting ill, being ill, getting better (or getting worse), and coping (or failing to cope) with illness, can all be thought of as enacted narratives within the wider narratives (stories) of people's lives.

Narratives of illness provide a framework for approaching a patient's problems holistically, and may uncover diagnostic and therapeutic options.

Taking a history is an interpretive act; interpretation (the discernment of meaning) is central to the analysis of narratives (for example, in literary criticism).

Narratives offer a method for addressing existential qualities such as inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people's illnesses.

The lost tradition of narrative should be revived in the teaching and practice of medicine.³

To the critics who state that storytelling does not reach the criteria set out under the principles of evidence based medicine, the final article offers this rejoinder:

Even "evidence based" clinicians uphold the importance of clinical expertise and judgment.

Clinical method is an interpretive act which draws on narrative skills to integrate the overlapping stories told by patients, clinicians, and test results.

The art of selecting the most appropriate medical maxim for a particular clinical decision is acquired largely through the accumulation of "case expertise" (the stories or "illness scripts" of patients and clinical anecdotes).

The dissonance we experience when trying to apply research findings to the clinical encounter often occurs when we abandon the narrative-interpretive paradigm and try to get by on "evidence" alone.⁴

3 Greenhalgh T, Hurwitz B. Narrative based medicine: why study narrative? *BMJ*, 1999 Jan 2, 318(7175): 48–50.

4 Greenhalgh T. Narrative based medicine: narrative based medicine in an evidence based

*”Ask yourself what’s right and wrong—
Storytelling in Health Professions Education*

Not surprisingly, the most discussion regarding storytelling in health professions education occurs in the nursing literature. Davidhizar and Lonser classify storytelling methods used in the teaching setting into three types: stories that role model good and bad interventions; scenarios, case studies, and vignettes for analysis; and the use of reflective analysis. The last method calls for reliving clinical experiences and analyzing it in a manner similar to a “debriefing”.⁵ All three methods can be used to enhance learner self-esteem, to develop critical thinking, teach ethics, teach cultural sensitivity, provide role modeling and to teach communication. While this study was based on classroom teaching, it is possible to use these methods in other settings as well, for example through written vignettes inviting reflective analysis of the readers in a group setting.*

Other, more literary formats have been used to reach similar goals.

world. *BMJ*, 1999 Jan 30; 318(7179): 323–5

5 Davidhizar R, Lonser G. Storytelling as a teaching technique. *Nurse Educator*, 2003, 28 (5): 217–221

* For example, this author’s “Draw the Line II: Professionalism” project, sponsored by the Association of American Medical Colleges, used vignettes with ethical and professional quandries to reach large group audiences.

Ness used short stories and Shapiro and Rucker used poetry in their studies of teaching humanities to medical students.^{6,7} Ness chose to do close analysis of the literary aspects of the works, and tried to have his students experience the author's various views of what made up the doctor-patient interactions. The biggest arguments amongst students were about the motivations of the characters involved. They found that by the end of the course, they had developed a sense of awareness of complex interactions among people and their feelings, thoughts, backgrounds, and motivations. They also considered their own psyche and how they could maintain personal awareness themselves as they cope with modern medicine. While Shapiro and Rucker's article focuses more on the structure of their course, they note that their success would not have been possible without supportive institutional leadership and "buy-in" from other faculty. However, in another article, Shapiro and Liu discuss their use of literature (in this case, short stories) to help students learn how to manage the so-called "difficult" patient.⁸ They also outline a set of questions to be used after each reading selection to encourage reflective analysis, moving from basic factual queries ("Who is the speaker?") to evaluative considerations ("How did you feel about the

6 Ness DE. Short stories about doctors and patients: a course. *Academic Medicine*, 1989, 65: 234–235

7 Shapiro J, Rucker L. Can poetry make better doctors? Teaching humanities and arts to medical students and residents at the University of California, Irvine, College of Medicine. *Academic Medicine*, 2003, 78: 953–957

8 Shapiro J, Lie D. Using literature to help physician–learners understand and manage "difficult" patients. *Academic Medicine*, 2000, 75: 765–768

narrator?") to interpretive ("What message can you take back to clinical practice from this selection?").

There can be other uses of story as well. Evans and Severtsen discuss their use of storytelling to teach nursing students about cultural assessment, by telling stories in a group and modeling gentle questioning and teasing out the meaning of the story as a whole, rather than as analytical fragments.⁹ Looking for meaning in stories, sensing the values and beliefs in them, and suspending their own cultural biases were all part of the process. In the same way we ask story listeners to suspend disbelief, in this context, we can request that they suspend other assumptions.

Empathy can also be taught through narrative and story. Three articles by Dasgupta, Fairbairn and Jones all relate this concept, using methods ranging from personal illness narratives to hypothetical stories.^{10,11} Jones goes on to state important principles regarding how narrative functions in the study of medical ethics:¹²

Narrative contributes to medical ethics through the content of stories (what they say) and through the analysis of their form (how they are told and why it matters)

The study of fictional and factual stories can be an important aid to understanding in medical ethics.

The techniques of literary criticism can be applied to the analysis of

9 Evans BC, Severtsen BM. Storytelling as cultural assessment. *Nursing and Health Care Perspectives*, July/August 2001, 22(4): 180–183

10 DasGupta S, Charon R. Personal illness narratives: using reflective writing to teach empathy. *Academic Medicine*, 2004, 79: 351–356

11 Fairbairn GJ. Ethics, empathy and storytelling in professional development. *Learning in Health and Social Care*, 1(1): 22–32

12 Jones AH. Narrative in medical ethics. *BMJ*, 1999, 318: 253–6

ethical texts and practices and can inform the understanding of different perspectives in an ethical dilemma.

To understand and accept a patient's moral choices, a practitioner must acknowledge that the illness narrative has many potential interpretations but that the patient is the ultimate author of his or her own text.

In a 1992 work, Hensel and Rasco discussed the use of storytelling to teach values and attitudes.¹³ They also discuss the problem of storytelling not only being ignored, but treated in a pejorative sense due to several failings story has as a clinical tool: it serves as a poor description of both disease and disease pathophysiology, the myriad perspectives a story can take, and the use of story one or more steps removed from the clinical encounter itself. At the same time as accepting these failings, however, they make the point that storytelling has immense value, assuming that the problems are considered. By the well-crafted use of a compelling story, “students and residents [can] discuss and overcome their crises of professionalization and come to grips with the troubling aspects of the doctor–patient relationship.”

Finally, as an example of a narrative of a different sort, a project endeavoured to organize performances of the Pulitzer Prize-winning play *Wit* at multiple medical centers followed by structured discussions of the play's themes.¹⁴ They found that participants “confirmed the appeal, emotional

13 Hensel WA, Rasco TL. Storytelling as a method for teaching values and attitudes. *Academic Medicine*, Aug 1992, 67(8): 500–4

14 Lorenz KA, Steckart MJ, Rosenfeld KE. End-of-life education using the dramatic arts: the *Wit* educational initiative. *Academic Medicine*, May 2004, 79: 481–486

impact, and perceived relevance of drama in end-of-life education.” Teaching through story need not only be words on a page.

*”Speak for me’ Scherezade—
Storytelling with Other Professionals*

Storytelling should not be discontinued simply because of a lack of a classroom teaching setting. In fact, it can be very useful in helping communicate information and concepts to fellow professionals as well as in evaluating research and other work. An example in which communication is enhanced is found in an issue of *Academic Medicine* where a series of articles used storytelling to tell the narrative of eight medical schools which reformed medical education in different manners. These progressive tales, using interspersed direct quotes together with a summation of “lessons learned” appearing at the end, provided a novel view of the subject.¹⁵ As the editors of the project say in their summary:

...we also believed that the richness of our experiences resided in the narratives of our individual and collective stories. Consequently, this supplement does not present a traditional quantitative research effort. It is not intended to be an exhaustive compilation, and it does not contain quantitative data or *p* values. It presents a qualitative reflection on curriculum change and provides a perspective on what did and what did not work.¹⁶

15 Lindberg MA. The process of change: stories of the journey. *Academic Medicine*, 1998, 73: 4S–10S

16 Krackov SK, Mennin SP. A story of change. *Academic Medicine*, 1998, 73: 1S–3S

A common criticism is that storytelling is not in keeping with the scientific method. Bailey and Tilley examine the methodological issues behind storytelling in research settings, reviewing the use of stories about chronic illness, particularly chronic obstructive pulmonary disease.¹⁷ In their ethnographic study, narrative analysis found some important results, such as a story told twice with different meanings and a patient's "death story" used to communicate distrust of a nurse's ability to recognize the seriousness of distress. As they point out, "It is therefore *meaning* not *truth* that the qualitative researcher wishes to understand."

This is taken further in an article by Koch, considering how interpretive work can result in a valid research product.¹⁸ By reviewing interrelated domains of interpretive research (journaling, observing, listening, writing and rigour), she asks us to consider the research process as a reflexive exercise which asks "what is going on?" in this process.

In a somewhat different vein, Sobel argues that the standard process of the medical case history, while a tested method for enquiring about a disease state, has become part "of the dehumanizing flight from sensitive subjectivity to sanitized objectivity, from human interest to 'science.'"¹⁹ He

17 Bailey PH, Tilley S. Storytelling and the interpretation of meaning in qualitative research. *Journal of Advanced Nursing*, 38 (6): 574–583

18 Koch T. Story telling: is it really research? *Journal of Advanced Nursing*. 1998, 28(6), 1182–1190

19 Sobel RJ. Eva's stories: recognizing the poverty of the medical case history. *Academic Medicine*, 2000, 75: 85–89

argues that while significant change to the process of the medical history is unlikely due to the twin needs of usefulness and tradition, medical professionals should remind themselves of the flaws in the process. He illustrates this idea by telling the story of ‘Eva’, a dying woman. He does this first as a case presentation, following it with an author’s depiction of this same woman, who is in fact a character from a short story. The contrast is rich and reminds us of “the erasure of the unique individual from his or her disease.”

Myers focuses on the storytelling aspects of the doctor-patient relationship itself, analysing how patients have “lost their voice” in modern medical encounters.²⁰ He discusses various views, among them the “holistic critique” posits that modern medicine is reductionist and therefore excludes the psychosocial dimensions of their health. He also discusses the “postmodern critique”, in which the patient’s voice is lost due to medicine’s desire for an illusion of mastery and control over situations where things have “gone wrong”.

He offers a third view, stating that physician-patient encounters are a remnant of “archaic healing rituals”, an attempt to restore order to life that has been disrupted. In his view, the illusion of control is primary necessary

20 Myers GE. The storytelling dimension of the physician-patient relationship. *Queen: A Journal of Rhetoric and Power*. 2001, <http://www.ars-rhetorica.net/Queen/VolumeSpecialIssue/Articles/Myers.html>. (Accessed 25 April 2004.)

in order to locate hope in the arena of beating mortality. The establishment of this illusion, he argues, is centered in the creation of a joint narrative between the physician and patient in which hope at “beating death” can occur. While not necessarily an explicitly conscious use of story, it is a form of storytelling-as-creation of a potential future for the patient.

Finally, it is important to remember that stories and case knowledge interact and overlap in profound ways. Cox makes four points regarding this interplay:

First, clinical stories recount pointed examples of ‘what happened’ that expand our expertise in handling ‘a case like that’. Second, cases are the unit of clinical work. Case stories expand the dimensions and details of case knowledge, case-based reasoning, and case management. Carefully collated case stories can comprise the ‘real life’ clinical curriculum. Third, stories provide a framework for ‘web’ or ‘net’ thinking that links all the objective and subjective details within the multifaceted complexity of case management. Fourth, personal stories explain how both numerical and non-linear influences determined what decision was actually made in that case.²¹

Rather than previous views discussed of story and clinical presentation being diametrically opposed in intention, Cox prefers a viewpoint where the two work together to provide a more complete picture.

”Je veux savoir I want to know—
Storyte, ing with Patients*

Storytelling can, of course, be used directly with patients. Above we

²¹ Cox K. Stories as case knowledge: case knowledge as stories. *Medical Education*, 2001, 25: 862–866

discussed the use of narrative methods and principles to interpret interactions, but the explicit use of story with patients can have great promise. Children, of course, are one of the best targets for the use of story since their willingness to suspend disbelief and accept a “story world” is far greater than adults.

Pain narratives in children can be difficult to deal with – often their narrative is not directly in congruence with physical findings, and can lead to accusations of the child being untruthful. By sharing pain narratives with children, health care professionals can become “in-relation” with them – meaning that they can engage meaningfully in a manner that “acknowledges our moral obligation to care for and with them about their pain.”²² Children who are in chronic pain learn to report their findings in a clinical fashion that pleases professionals (“a sharp, piercing pain in my left lower abdomen, six out of ten.”) However, this does not allow them to express (nor the provider to capture) the fullness of the pain and what it may mean to the child. “Sharing their narratives allows us to start to appreciate how pain ‘unmakes’ worlds (Scarry 1985); how pain can radically alter the child’s bodily integrity, their sense of self, their life-world.” As Carter notes, to understand the pain, we need to prepare to feel it ourselves, to be hurt by it. He tells us that “children may tell us stories that have been broken by their

²² Carter B. Pain narratives and narrative practitioners: a way of working ‘in-relation’ with children experiencing pain. *Journal of Nursing Management*, 2004, 12: 210–216

pain; by being in-relation with them through their stories we can help them ‘fix’ their stories.” This is necessary to meaningful contact with children in a healing setting:

Ethical engagement with children through their stories does not simply mean working within a particular code of conduct. It means engaging with children’s pain on their terms. It means listening to and noticing the things that the children perceive as important.

Not only should story be listened to, sociocultural aspects of the story should also be considered closely and used in adapting responses.²³

Besides being recipients of narrative, health care providers can be the tellers of stories. It can provide a vehicle to address chronic illness, human nature, death, dying, and advance directives.²⁴ Story can provide a metaphor of a journey for patients who are facing a long, complex path of treatment.²⁵ While strongest with children, who may have an altered sense of time and progression, adults can benefit as well. In an ideal situation, members of the health care team as a whole can tap into the context of a story to use it as a way of signposting important events in treatment and helping with the fundamental issue of expectation management.

Additionally, according to Keding, story can provide a non-pharmacological way to control temporary physical pain. By telling a story to

23 Smith GG, Celano M. Revenge of the Mutant Cockroach: Culturally Adapted Storytelling in the Treatment of a Low-Income African American Boy. *Cultural Diversity and Ethnic Minority Psychology*, 6(2): 220–227

24 Kirkpatrick MK, Ford S, Castelleo, BP. Storytelling: An Approach to client-centered care. *Nurse Educator*, Mar/Apr 1997, 22(2): 38–40

25 Keding D. Personal Interview, 3 May 2004.

a patient and having them learn it, they have the option of repeating it to themselves from memory in a manner similar to certain meditation techniques. Story can also act to provide instruction that may not be received so well told outside of a story setting. Allowing a patient to interpret a story's meaning so that they consider "getting their affairs in order" in a terminal situation can mean more than directly telling them the same thing bluntly. Parables can be particularly effective, as they are short and can be told in the context of a busy clinical setting.²⁶ They also carry a moral message or instruction that is usually easily discernible.

In many cases, the patient is not only the individual, but can also be families or communities at large. Speaking at a memorial service, a support group, or another large group can also be an opportunity to use story, and there are collections which are arranged in that fashion for use.^{27,28}

However, while it is easy to extol the virtues of storytelling, it is important to realize that there are limits to what it can do. Greenhalgh, who we have seen is a strong advocate of storytelling tells us, in a commentary on the previously mentioned article by Cox:

We all learnt the value of stories at mother's knee, and Cox's article makes a

26 A good collection of parables is Feldman C, Kornfield J. *Stories of the Spirit, Stories of the Heart: Parables of the Spiritual Path from Around the World*. New York, HarperCollins, 1991. Another is Outcalt T. *Candles in the Dark: A Treasury of the World's Most Inspiring Parables*. Hoboken, Wiley, 2002.

27 Livo NJ. *Story Medicine: Multicultural Tales of Healing and Transformation*. Libraries Unlimited, 2001.

28 Cox AM, Albert DH. *The Healing Heart: Communities and Families*. New Society, 2003

lot of intuitive and humanistic sense. But in terms of behavioural and patient-relevant outcomes, the evidence as presented does not yet support the story as the preferred unit of approach and analysis in all aspects of health care. Cox's evidence is equally consistent with a more eclectic and targeted use of stories — to supplement, rather than replace, other forms of learning and training. But educationalists should not allow different degrees of scepticism towards storytelling to divide their common purpose. We should all recognise the need to continue to explore, document, and critically evaluate our various experiences with this powerful technique, so that the next generation can draw definitive conclusions about its usefulness in different contexts.²⁹

Conclusion

Storytelling has many facets and uses in health care. We've touched upon the implications for education, the value in using story to work with other professionals, and the power of story in working with patients, families and communities. Story lets us step outside of our usual roles and hold discussions, debates, and teach in a safe place where we can let go of some of our prejudices and assumptions. Not only does it permit health care providers to do their jobs more effectively, but it allows a wider casting of the role of health care in society. Effective use of narrative helps break down barriers and reduce the notion of the "other" that can keep distance between patients and providers. As Charon states:

The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Medicine practiced with narrative competence, called *narrative medicine*, is proposed as a model for humane and effective medical practice.

²⁹ Greenhalgh T. Storytelling should be targeted where it is known to have greatest added value. *Medical Education*, 2001, 35: 818–819

Adopting methods such as close reading of literature and reflective writing allows narrative medicine to examine and illuminate four of medicine's central narrative situations: physician and patient, physician and self, physician and colleagues, and physicians and society. With narrative competence, physicians can reach and join their patients in illness, recognized their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care. By bridging the divides that separate physicians from patients, themselves, colleagues, and society, narrative medicine offers fresh opportunities for respectful, empathic, and nourishing medical care...

By bridging the divides that separate the physician from the patient, the self, colleagues, and society, narrative medicine can help physicians offer accurate, engaged, authentic, and effective care of the sick.³⁰

Well said.

³⁰ Charon R. Narrative medicine: a model for empathy, reflection, profession and trust. *JAMA.*, 2001, 286: 1897–1902



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