Patients Telling Stories to Doctors in a Technological Age

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My story

• Past – Once upon a time

• Event – and then one day

• Future – and then and then hopefully resolution

• Yet there is more to the story

Derived from Ray Barfield MD, PhD
Stories and Technology – My Thesis

• Humans are story telling animals (discussed by philosophers for centuries – the unique role of language)

• The technological press of modern medicine overwhelms the doctor (health care professional)-patient relationship.

• Technology is more than tools, it is the way we use these tools and how that process shapes our thinking and action (perhaps induces a ritual to deal with uncertainty). Think algorithm.

• Technology discourages stories at every turn by the nature of the process, the ritual (syncope requires a stress test)
Stories and Technology

- Our natural response to technology is to tell our story. It is a way we gain control and equalize the doctor-patient encounter.

- Not only is that story informative, it is sacred, an illness narrative somewhat like a prayer. A story embedded in a larger narrative.

- We must find space to hear the stories of our patients.

None of this may be especially new, yet it derives from my story and is unique to me.
My Story

• My story is a typical story, yet a story I felt a need to tell.

• The event that precipitated my story was addressed by competent and caring professionals who managed an emergent event well, but

• My story was not heard.
What they heard

Syncope → cardiac workup
Laceration → suture
Dehydration → fluids
N&V → meds
Duke faculty → Google
Psychiatrist → You can hear my story
What they didn’t hear

• Past history – a history of syncope

• Immediate History – from whom did I become infected

• Medicine I had used (Tylenol)

• I have a grandchild with whom I come in contact (could I infect her?)
What they didn’t hear

• I am very healthy and jog five times a week.

• The entire event seemed surreal to me
  – In a hospital where I have worked for 40 years the ED was a non-place
  – I did not know one person with whom I interacted
  – I did not know the time (the clock did not work)
  – I did not know what was coming next (I was disoriented)
  – I did not know what this event meant in terms of my overall health when I was discharged from the ED
We are storytelling animals

• Most agree that what sets humans apart from other animals is the development of language, which is born of community (we are not born speaking French but we are born to speak).

• Humans, among the animals, are among the most community oriented. Stories bind communities together – our personal stories embedded within larger stories (my story bound me to the ED and Duke Hospital as a patient).
  – e.g., Richard Adams: Watership Down

• All stories presume a past. If the past is irrelevant, we cannot tell stories. (The ED presumed that nothing but the immediate event was relevant.)
We are story telling animals

• Stories are not made up simply of facts (event – response). There is truth in stories, it is just not easy to tell with certainty. (Melville – “truth is always incoherent”)

• A traditional story is aware of its context – takes place somewhere. (My story occurred in context, yet my event could have taken place in any good ED.)

• A story assumes something happened (something is wrong) despite the fact that nothing “objective” is found to be abnormal (some come to the ED with unexplained pain and leave as if unexplained means a non-event – no story to tell).
We are story telling animals

• Traditional stories render events in such a way that they may not be averted - the Greek tragedy. Such stories assume problems that cannot be avoided or solved. (In technology all problems can potentially be solved. Yet all problems cannot be solved.)

• We are by nature spiritual (whether we are religious or not). Spirituality is a personal quest for answers to questions about meaning, about right behavior, about ultimate relationships. And meaning is found in the stories that define our spirituality, the “metanarratives”. (The ED is not about meaning making in a larger perspective.)
What about technology?

• Aristotle's concept of techne - that form of inquiry in which
  – the end/goal of a particular clinical encounter is specified in advance of the application of a particular “method” or “technology,”
  – the focus is on the selection of the method or technology which best attains this pre-specified end, and in which
  – the successful application of the method or technology does not depend on the moral character of the agent.

• Technology is here to stay and will become more omnipresent. There is no room for Luddites. (The ED is not going away and I don’t want it to go away.)

• Yet technology is not about stories with unknown endings and unclear methods of intervention.
What About Technology?

• Technology is therefore not new (tools of our ancestors). Medicine is simply “more” technical than in the past perhaps because we have more tools or have opened up more uncertainty given the vast increase in information.

• Technology is value neutral in theory, yet the value judgment that all problems are technological problems to be solved by technological solution is implicit.

• Technology is not without its critics and these critics lead more with intuition and story than facts Jacques Ellul and the “Humiliation of the Word”.
What about technology?

• Technology determines the procedure and free choice is subsumed into algorithms (good surgeons follow set procedures – better for them NOT to think too much. Wanted the intern to concentrate on suturing.)

• Technology focuses upon absolute efficiency (no room for “slow medicine”, e.g. *Victoria Sweet, “God’s Hotel”*). And there is a need in many settings for efficiency, especially and ED.

• Technology is devoid of mystery (though I might be enthralled with how the internet works, or the magic of the heart monitor).

• Technology discourages complex and complicated relationships (especially between doctors and patients. No doctor was interested in knowing me. They were not rude. They could not afford to know me. )
Technology does not tolerate stories

Technology applies knowledge for practical purposes independent of subjective dispositions, personal talents, or moral character of those involved. (Every patient in the ED is basically the same – no room for unique stories. I was unique being Duke faculty yet my story was not.)

Technology names the problem and by doing so defines the problem without story (Diagnoses including DSM-5 diagnoses eliminate the need for a “formulation.” My problem was syncope.).

Technology floods us with information, more than we can integrate into a story. (The information generated during my 36 hours in the ED was massive. My story could have been longer than War and Peace!)
Technology does not tolerate stories

• Technology subsumes the irrational into the rational (a good story must include the irrational – Sherlock Holmes is boring without Watson. I suspect I was boring except for the Google search. )

• Technology pushes standardization (the uniqueness of stories is collapsed into impersonality – my nomogram)

• Technology assumes that all problems can be solved and the outcome is achieved through technology. (A good story proceeds through chance, intuition, conflict, and mystery. Must have been frustrating that my story did not have a neat ending.)
Technology does not tolerate stories

• Technology focuses upon I-it relationships (the world of objective experience and sensation broken into separate entities). Stories focus upon I-Thou relationships which include the stranger into a set of persons who we draw into ourselves – the melting of the between so we stand in direct relationship with another “I”. **Martin Buber**

• Technology builds non-places (EDs, airport terminals, supermarkets, computer terminals – **Marc Auge: Non-Places**). Stories take place in context, somewhere. When I left the ED it was as if I stepped from a spaceship into the elevator bank of Duke North.
Our Response to Technology

We want to tell our story – my experience

– I wanted the caretakers to get my story right, to hear

– The long-winded older man in the bay next to mine in the ED drove his providers to distraction with his long-winded story

– Paradoxically, I heard a number of stories myself
  • The suicide of a nurses friend
  • The pain of a strained marriage
  • The use of superglue to heal a baseball wound
Our response to technology

• In many ways as doctors we have embraced and embodied technology which mutes our patient’s story.
  – When we press the accelerator to the floor we say “I am speeding up.”
  – We focus on signals of our choosing (response to a medical procedure or a score on a scale) and miss critical intuitive signals (e.g., the patient who returned to golf)
  – We are enamored with the visual, not the auditory (the image versus the word)
  – We have no time for curiosity, we do the next obvious thing. (One test abnormality leads to another test)

Yet our patients want to tell stories!
Our patient’s response to technology

They need to tell stories

• Illness stories are therapeutic for tellers. They want to be heard and to hear themselves tell *and retell* the story, to unravel the truth of their experience. (I am retelling my story to you.)

• They reform their sense of personhood through this process of telling a story of an unexpected and uncertain event. (A visit to the ED disrupted my sense of who I am.)
Our Response to technology

• In Western Society we are preoccupied with the “restitution” narrative (Arthur Frank: “The Wounded Storyteller”).
  – “Yesterday I was healthy”
  – “Today I am sick”
  – “Tomorrow I will be healthy again”
  – This is the narrative of technology, if there is a narrative.
Our Patient’s Response to Technology

• Yet those with chronic illnesses find it difficult to tell a story that has no happy ending in sight. Even more so they need the chance to tell their story and be heard.

• The chaos story is the most frequently unheard:
  – If illness is overwhelming, speaking coherently becomes impossible (an anti-narrative)
  – Listening to such stories is painful and frustrating.
Our Patient’s response to technology

They need to embellish the story

• In the sterile non-place of medical technology we desire to bring color, mystery, drama and music into the setting. They have a need to humanize the atmosphere.
  – The irrelevant is important (e.g., the fact that I regained consciousness thinking that I had returned to my bed, that the first thing I saw was a red and orange felt birdhouse).
  – The dramatic is important (e.g., I heard a crash, it must have been me falling)
Illness narratives are sacred stories

• Our shared illness narratives are in many ways like sharing in corporate prayer, a sacred activity.

• If we accept the spiritual, then current neurophilosophy posits that the spiritual is embodied.

  – The Descartes body-mind dualism does not hold

  – The spiritual, the sacred does not disappear when we enter the technological medical world (no separate and independent magisterium as suggested by Stephen Jay Gould: Rocks of Ages holds for our sacred illness stories).
Illness narratives are sacred stories

• Illness upsets our sense of balance between ourselves, the world, events and meaning. Telling a story is a way to restore that balance. We tell stories to provide context and therefore impart meaning in the service of balance.

• We tend to place serious events into a spiritual realm.
  – Stories reside in communities (the ED has no past, future, or community observable to the patient - yet I have a past and future with the community of my family).
  – My suffering is part of a larger story often embedded within a faith community – Stories lead to questions formed by these communities, such as, “Why did this happen to me? Is this a wakeup call about my life in community? Do I have my priorities straight?”
Illness narratives are sacred stories

• These sacred stories can be viewed as a reflection of the covenant between us and a higher being, but also a reflection of a covenant between fellow pilgrims.
  – This covenant is marked by candor, authenticity, confidentiality, not simply confession and petition.
  – Our patients may be speaking for others as well as themselves (I identified with all those who visit busy EDs. I will never view an ED the same again and when I hear stories of persons in the ED I can identify with them).
Illness narratives are sacred stories

• Our patient’s narratives include prayers for those of us who care for them. (Not discussing whether or how this might be appropriate.)

  – Why do our patients ask us to pray for/with them? In part that prayer brings us more intimately into their story, brings us in on a deeper level.

  – Why do our patients pray for us? If we are part of their story they care for us in the ways they feel they can just as we care for them.
Illness narratives are sacred stories

“Cancer points up our failure to explain and master much in our world. Perhaps most fundamentally, cancer symbolizes our need to make moral sense of “Why me?” that scientific explanations cannot provide”

Arthur Kleinman, Illness Narratives, 1989

Many illnesses fall into the same category
Illness narratives are sacred stories

• The ED (or hospital) may be an isolated experience for doctors but not for patients
  – Orpha, the hospital, and a very inexperienced intern.
  – Patients need to feel part of the community caring for them and to see that community as something special, sacred.
Implications

• Illness narratives, these sacred stories, are mainly for us to hear.
  – If we hear the story and can repeat back later that we have heard the story, that is most comforting to the patient
  – Sacred stories do not call in and of themselves for interpretation or action.
    • Elements call for action (laceration requires sutures)
    • Yet the overall story, like a prayer overheard, is to be respected and valued by the hearer
Implications

• We are privileged to hear these sacred stories.
  – Most of the stories are good stories, worth a listen if we but take the time

  – If we listen, we will remember these stories and they shape our lives

• Do we have the time to listen and hear stories?
  – We cannot hear all stories, perhaps even most.

  – Yet time may not be the most critical factor. Hearing stories is an acquired trait.
Implications

– We cannot afford a life in medicine devoid of stories.

• We must find time and space to hear stories.
• “the first principle was not medicine, nursing, or a balanced budget, but hospitality in the sense of taking care of anyone who knocked at the door because – it could be me.” Victoria Sweet: “God’s Hotel” about Laguna Honda.
• We must learn how to listen to stories actively, not to shape the stories to our own image, to interpret them but rather to help “birth” the stories.
• We must learn to retell the stories (case reports that are person oriented)
References

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