Evidence-based medicine and the anecdote: Uneasy bedfellows or ideal couple?

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Over the past 30 years, there has been a resurgence in the use of storytelling and narrative in medicine. At first glance, the trend to incorporate art forms into medicine appears to run counter to the rise of the more objective and positivist evidence-based medicine movement. In the present article, the authors provide examples of the use of storytelling and narrative in medicine, describe their origins, and contrast this approach with evidence-based medicine. The authors suggest that storytelling and narrative offer a complement to the science of evidence-based medicine. Finally, the authors describe a program of research to develop and evaluate the use of storytelling as a communication tool between physicians and parents/caregivers of children presenting to the emergency department.

Key Words: Anecdotes; Communication; Evidence-based medicine; Narration; Storytelling

Since the 1970s, there has been a renaissance of narrative/storytelling in the health care setting. Western practitioners are reinvigorating this lost art in an attempt to provide a more holistic and intuitive approach to patient care. This is evidenced in the growing body of medical literature on narrative/storytelling; in fact, a PubMed search using the term ‘narrative OR story’ yields almost 12,000 citations. Furthermore, medical schools across North America are incorporating arts programs, more specifically literature courses, into their curricula (1,2). The objectives of the present paper are to provide an overview of narrative/storytelling in medicine; discuss narrative/storytelling in the context of evidence-based medicine; and describe a program of research to evaluate the effectiveness of storytelling as a communication tool in the emergency department (ED). While some authors distinguish between narrative (consciously formulated, premeditated and coherent account [3]) and storytelling (informal relating of events), others use the terms interchangeably (as we have in the present paper).

Evidence-based medicine was cited by The New York Times (4) as one of the major, innovative ideas in 2001. Still, we know that there may often be a lag of 10 to 20 years between the availability of evidence and the application of recommendations for routine use in major textbooks (5). Critical gaps remain between what is known and what patients receive as their standard care (6). While evidence-based medicine represents an important advance in the history of medicine, its full potential is thwarted if patients do not receive the benefit of the latest research.

Contrast this with the rapid uptake of potentially new but unproven interventions, when framed in the context of a powerful anecdote. Parker Beck was a four-year-old boy who had developed autistic symptoms at the age of two years. In an effort to determine the source of constant diarrhea and vomiting, he underwent an endoscopy, during which he received intravenous secretin. His parents subsequently noted a rapid and dramatic improvement in his autistic symptoms. This remarkable story (7) aired on NBC’s Dateline in October 1996:

“It seemed Parker no longer heard his parent’s voices. He stopped talking, stopped sleeping through the night and began oddly spinning…Parker was showing all the symptoms of autism, one of the most terrifying and hopeless diagnoses a parent can hear…Imagine your child disconnecting from the world, (a) child whose eyes look, but don’t see, whose ears hear, but don’t listen, whose cries never end and doctors offer little help.”

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The story continued by recounting the events following the endoscopy:

“A few days later, something completely unexpected happened. Parker’s diarrhea disappeared and he began sleeping through the night for the first time in two years…Parker, who had been totally nonverbal, was now reciting flashcards as quickly as (the therapist) could hold them up. For Victoria and Gary, it was nothing short of a miracle. Their little boy was back, talking and listening.”

The story was so powerful and convincing that it created an immediate and dramatic response. Many parents and caregivers approached their health care providers demanding this new and ‘effective’ treatment for their autistic children. Fortunately, there was a rapid response from the research community. Fourteen randomized controlled trials were performed after this story appeared, none of which supported the effectiveness of secretin as a treatment for autism (8).

This type of situation can be very frustrating for evidence-based proponents. They believe that the evidence is what is best for patients. Yet a simple anecdote may often prove more powerful in persuading other health care providers or patients and their families to adopt a particular approach to management.

The verbal transmission of medical traditions reaches back to our earliest attempts to communicate, eventually uncovering and illustrating the effectiveness of a medicine by telling the story around its application and successful conclusion, or conversely its failure. Information is handed down from generation to generation via the story about how something worked, how it worked, and why it is so very important to maintain the tradition, protect the knowledge, and share the burden of this wisdom. Nomadic people had no better place than their brains to carry the weight of their continually expanding collective knowledge of how to survive in their world.

Cognitive psychology may help to explain the continued use of storytelling that transcends culture and time, in that there is evidence that the human brain may process stories better than other forms of input. Humans have been described as “primates who tell stories”, and that they are “primates whose cognitive capacity shuts down in the absence of a story” (9). Stories are an integral part of learning (10). Stories play a key and powerful role in the early education and development of young children. The world’s most renowned teachers have used metaphor and stories for centuries (11).

Despite the power of storytelling and its universal appeal, its use in Western medicine in the past century has been usurped by more positivist, objective approaches to the practice of medicine, a reductionistic understanding of disease (1) and the rise of modern technology.

So, how did we get to this point? In an elegant piece in The New York Times, Thernstrom (2) wrote:

“Once upon a time, until the last century or so, doctors had little in their tool bags except their humanity with which to channel that mysterious thing we call a healing encounter: that charged interaction – personal and impersonal, physical and spiritual – upon which so much depends. Now that blood tests have replaced bloodletting, how can we make that interaction be more rewarding?”

This led to our formulation of a theory that there may be an inverse relationship between science and the intuitive and narrative aspects of medicine (Figure 1). But must the intuitive/narrative side of medicine necessarily succumb to the rise of evidence-based medicine? There are an increasing number of health care practitioners who are seeking to find balance between the two.

Narrative is used in many contexts, such as diagnosis (12,13), therapy (14-16), and the education of patients, students and practitioners (1,17-21). Historical examples of the use and value of narrative are abundant. In the context of paediatrics, a passionate debate over the optimal management of croup aptly demonstrates the frequent rift between anecdote and evidence. The discussion over the past 40 years at times has fallen between the ‘town and gown’ groups, or between the anecdote and evidence-based groups. In the early 1970s, Dr Coffin (22) wrote in a letter to the editor (‘Corticosteroids in croup: Is there a reply from the Ivory Tower?’), in which he stated:

“…I would like to state unequivocally that I am strongly in favor of their (corticosteroids) use and feel certain that they contribute a great deal to the reduction of morbidity and the necessity or endotracheal intubation…I must contest, then, the double blind studies which reveal no benefits of steroids in croup…It is all very well for those who are practicing in the ivory tower atmosphere of pediatric departments to run their double blind studies caring little whether or not they are causing several croup patients to have unnecessary surgical procedures.”
Anecdote and evidence-based medicine

In a letter entitled ‘Reply from the ground level’, Dr Menachof responded (23):

“The letter by Coffin demonstrates very clearly unacceptable reasoning. His unequivocal endorsement of the use of steroids in viral croup is equally irrelevant to my own 12 years’ experience demonstrating the failure of steroids to affect the outcome…”

In the end, ironically, the evidence firmly supported the anecdotal position of Dr Coffin, perhaps foreshadowing the potential complementary nature of the anecdote and evidence-based medicine.

The incontrovertible value of stories prompted us to consider their use in our encounters with the parents and children under our care. Out of this emerged a concept: why not use the stories from parents of children who have a disease to help other parents learn about the disease and the role of evidence in managing an illness? Thus, we embarked on a research program to investigate storytelling as a communication tool, whereby evidence and information are transcribed through a form in which the focus is the personal experience of the family and patient rather than the technical details salient to medical care and bodily functions (24).

There are few precedents in the medical literature for the use of storytelling in this context. There has been some pilot work done through the Centre for Global eHealth Innovation (‘the Centre’) at the University of Toronto in Toronto, Ontario. In a study completed in 2001, researchers explored the value of storytelling in the context of screening for colorectal cancer (25). The initial small study involving 16 patients evaluated stories delivered through the Internet. The researchers found an increase in participants’ knowledge, but there was no impact in terms of ease of decision-making. Furthermore, while participants generally liked the idea of sharing information through storytelling and the Internet, the acceptability of the Web page varied according to the personal preferences of the participants. Currently, researchers at the Centre are evaluating a Web site called “Things that matter: Stories about living with colorectal cancer” (<www.storiesthatmatter.com>). Stories of patients with colorectal cancer, complemented with photography, can be viewed with or without sound and animation.

Our hypothesis is that we can effectively translate knowledge regarding the natural history and therapeutic management of a patient’s condition by couching it in a story that engages the reader by providing perspective, context, emotion, compassion and understanding. Storytelling may be especially appropriate in the paediatric setting, where “the family is the patient”, and in which the patients are characters in a story that begins before and continues after the visit to the ED. Moreover, the experience transcends that documented in the medical chart (26). Our belief is that the stories reduce parental anxiety; improve the parents’ satisfaction with the medical encounter and the patient-provider exchange; inform parents about the condition, its natural history and its management; and assist in decision-making, where applicable. Ultimately, we hope that this tool will optimize patient outcomes and resource use in the ED.

The first step in our program of research was to gather parents’ stories, using croup as the initial target condition. We chose croup based on several factors, including the frequency of presentation to the ED, the anxiety it causes parents, the strength of evidence for its management, and our familiarity with the condition and the evidence. The creative writer (JK) scheduled regular shifts in the ED, recruiting parents who were willing to tell their story. The writer also followed-up by telephone 10 to 14 days after the ED visit to gather further information. Subsequently, the writer developed a number of stories that reflected the experiences of the parents and covered the spectrum of disease severity, ranging from the child with very mild croup to the child with a more severe form requiring admission to hospital (see Appendix).

The stories were evaluated for clinical accuracy and appropriateness by two ED physicians and an ED nurse. They were also reviewed by a convenience sample of individuals for interest, style and clarity. Subsequently, extensive revisions were made to the stories, and the convenience sample of individuals provided additional feedback. Once the stories were complete, a graphic designer and illustrator worked together with the research team to develop story booklets that presented the stories in a visually attractive and engaging format. The booklets will be evaluated through a structured focus group involving eight to 10 parents. Final revisions will be made to the story booklets in response to the results of the focus group evaluation.

We will test the effectiveness of the final product through a multicentre randomized trial. Consenting parents/caregivers who meet predefined inclusion criteria will be randomly allocated to receive the story booklet or a standard ED information sheet. Parents will be contacted at one and five days following their ED visit. Our primary outcome will be state anxiety of the parent/caregiver, which will be measured using two validated instruments. Secondary outcomes include parental satisfaction and comfort with the ED visit and the information they receive; parental knowledge; parental decisional regret; ongoing symptoms; health care utilization patterns; and costs to the families and the health care system. Ultimately, we would like to test our hypothesis for different medical conditions and using different forms of presentation, such as videocassettes, Web sites and interactive computer games.

Will the union between the intuitive/narrative aspects of human interactions and evidence-based medicine work? Some might argue that this alliance goes against the principles of evidence-based medicine, which are so highly valued and touted in today’s practice of medicine. Others, however, note that the father of evidence-based medicine himself claimed that effective medical care requires an integration of sound evidence with fine clinical acumen (27,28). Supporters of the narrative movement would argue that this clinical acumen develops with an ability to see and understand the person behind the symptoms.
Kosko et al

For too long, a polarization has existed between the evidence-based medicine purists and those who value intuition as a key and important part of clinical practice (29). Still, superb clinicians skillfully incorporate the features of intuition in their practice (29). Our premise is that the combination of anecdote and evidence is complementary, not competitive. As our story unfolds, we will see how our hypothesis measures up — using evidence-based methods, of course!

APPENDIX

Storytelling for croup: Excerpts from stories based on experiences of parents attending the emergency department for the treatment of a child with croup

Excerpts from Story 1 – Things We Take for Granted: A Mother’s Account of Her Child’s Struggle with Croup

The nurse at the emergency department took us to an examination room right away. Matthew, who was now feverish, struggled with every breath in and coughed with every breath out. We had not waited long before the doctor came in. She read the chart and asked me some questions.

She listened to Matthew’s chest and announced, “Your son has a severe case of croup.”

I was confused. First, our family doctor told me that Matthew just had a cold. Then the doctor at the walk-in clinic said he had asthma. Now I was being told that he had croup. Were these the same thing? Why couldn’t anyone get it right? And how many more times was I going to have to answer the same questions?

* * * *

The doctor explained that they would give Matthew a drug called epinephrine through a mask, and that this would help him breathe. She explained that the epinephrine helps right away but doesn’t last very long, so they would also give him a steroid called dexamethasone. The steroid would help with the swelling in his throat and make it easier for him to breathe, but it would take a few hours to work.

The nurse put the mask over Matthew’s nose and mouth. Matthew became very upset. He was crying and trying to pull the mask off. I held the mask in place for several minutes and Matthew’s breathing became much easier. Then the nurse lifted the mask and quickly squirted the dexamethasone syrup into his mouth with a syringe.

Excerpt from Story 2 – The Switcheroo

Though living in her mother’s basement suite with her 13-month-old son, Kimi often called her grandmother to ask for help with medical issues; she was the community’s traditional healer, after all. Kimi had applied all the traditional medicine she could think of, but Uriel was still coughing and fighting for breath. Tonight, nothing seemed to help. Kimi often wished she were older; being a teenage mom, Kimi’s confidence in her skills as a parent was sometimes shaky. Kimi realized that she had no choice but to take her son to the hospital; she would have to wake her mother and ask her to drive them to town.

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