

A Whole Other Story: Interpreting Narrative Medicine

Kristen Salana, BA¹, Shauna Maty, BA, MPH¹, and Robert Hage, MD, PhD, DLO, MBA¹

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Abstract

The practice of conventional medicine is rooted in the ability of a patient to effectively communicate with their physician, and for the physician to comprehend the patient's story and perceive it through the lens of evidence-based practice. In reality, the differences in environmental backgrounds hinders this exchange of information and prevents a shared understanding and strategy. Narrative medicine provides a framework in which this divide can be bridged by encouraging the clinician to develop an appreciation of cultural nuances that drive a patient's decision making. The importance of this practice is highlighted with four stories in which the only path to competent patient management was through the utilization of narrative medicine.

Keywords

narrative medicine, patient communication, global health, Interpretation

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Introduction

Imagine the following scenario: a middle-aged woman wakes up one morning in her home, and immediately notices a few bluish spots on her arm. What are these, and how did they get here?

Unsurprisingly, the methodology used to determine what ails her varies based on where she resides. For example: if this woman is living in a village in the Caribbean, she would likely turn to her neighbors to discuss the blue mystery spots. Word would spread quickly, as it does in tight-knit communities, and most of the village would hear about the strange occurrence. The villagers would hypothesize that she had an overnight visit from a soucouyant, a Caribbean cultural folktale character who takes the shape of an old woman by day and a fireball by night once she strips off her skin and leaves it in a mortar.^{1,2} She flies through the dark sky in search of a victim, then sucks their blood from their arms and legs, leaving blue marks on the skin for the victim to discover in the morning. Someone in the community surely would know someone, who had a similar occurrence, and they would share their remedy with the affected woman. Additionally, all the neighbors would offer to help catch the soucouyant. The

woman's ailment is thus taken care of in a small community setting, remedied by her neighbors who are brought together and moved to action through a folktale that is handed down from and through their ancestors.

If this same scenario occurred in the United States, it can be reasonably assumed that the woman would not turn to neighbors and community members first. Depending on the nature of the blue spots, she might initially tell her immediate family, consult with her physician, or proceed with a trip to the emergency room. While in the ER, she would wait to be seen by a nurse who would take down her vitals, wait to be seen by a physician who would run through a series of questions and conduct a physical examination, wait for various laboratory tests, and then wait for results before knowing her diagnosis and treatment options.

¹Department of Anatomical Sciences, St. George's University, St. George's, Grenada, West Indies

Corresponding Author:

Kristen Salana, Department of Anatomical Sciences, St. George's University, St. George's, Grenada, West Indies.

Email: ksantana@sgu.edu



Examining how the ‘blue spots’ are addressed differently in these two regions is not meant to establish a superior and inferior form of health care. Rather, these region-focused scenarios provide medical trainees with an opportunity to develop a logical and emotional dexterity to help deliver the best care and treatment for patients. A physician can develop this framework based on models such as biopsychosocial medicine and patient-centered medicine. Kaplan-Myrth writes, “each patient brings a story to the practitioner. That story enmeshes the disease in a web of meanings that only make sense in the context of a specific life.”³ The author goes on to say that according to medical anthropologists illness narratives are more than just descriptions of symptoms, they are a process by which people become aware of and make sense of their own lives.³ Narrative Medicine was added to the medical lexicon in 2001 by Charon as a tool in the provision of empathetic, quality patient care. In 2016, a committee of international experts defined narrative based medicine as “a fundamental tool to acquire, comprehend, and integrate the different points of view of all the participants having a role in the illness experience.”⁴

Though the phrase and official definition are relatively new to medical terminology, narratives themselves have been an integral and important aspect of vocal communication and writing, typically transcending numerous generations.^{5,6} Unsurprisingly, narratives are an important part of medicine as well. As the renowned physician William Osler stated in the nineteenth century, taking a good history involves listening to the patients’ story since often, the patient will tell you the diagnosis.⁷⁻⁹ Since the publication of the Flexner Report in 1910, the focus of medical practice has been centered around a biomedical framework.¹⁰ Aligning with this, for many Western medical practitioners the initial patient workup lies in ordering a battery of laboratory tests and imaging due to constraints that limit time spent with a patient building a joint understanding. Thus, the patient narrative in the practice of medicine is lost in the shuffle of high volume, modern medicine.

When speaking to a patient, attention to their words, details given, emphasis, emotional and facial expressions are all imperative to understanding how the patient comprehends what is going on. Appreciation of these details establishes an important bridge for the physician to better understand the patient. By understanding how a person perceives their health related issues, much can be revealed about the patients themselves. For example, in the 19th and early 20th centuries in the South American country of Suriname, many people believed that “treef” and “tyina,” personalized food taboos, were the cause of leprosy and violations of such taboos could result in disease.¹¹ As rates of leprosy have declined in this

population, taboo violations have been associated with other illnesses. Similarly, the totemism belief system endorses that humans have a mystical relationship with a spirit being, such as an animal or plant, and implies that killing or eating said spirit can have severe repercussions on health and longevity. Furthermore, in some Caribbean villages psychiatric conditions are seen to be derived from a “bacoo spirit” summoned by a villager attempting to extract wealth from the afflicted in exchange for human life.¹² Drawing these types of conclusions can be described as a form of abductive reasoning. Patients will use abductive reasoning, which has been defined as using inference to explain a cause and an effect, when the relation between the two is not readily observable.^{13,14} This concept offers an explanation for the premise behind the four stories to follow.

Therefore, good communication to make sense of the full story is important to handle explanatory pluralism. The physician needs to integrate the details of the narrative and intertwine them with their medical knowledge and experience to arrive at a diagnosis that they will be able to effectively communicate back to the patient.

Discussion

The following are four different stories based on true clinical encounters in the Caribbean. These stories reveal the impact cultural narratives can have on health care and diagnosis, and why cultural competency and narrative based medicine are integral frameworks to develop quality patient care, understanding, and a therapeutic physician-patient relationship.

Story I

A 72-year-old man is brought to the emergency department by his daughters because of difficulty with swallowing and a severe breathing problem. His medical records mention an advanced hypopharyngeal cancer.

“Mr. X, I can hear and see you are having difficulty breathing and that is because of something blocking your windpipe. The best option now is to make an opening in your neck to bypass the obstruction, which will allow you to breathe much better. We then have time to discuss what to do next.”

“No, no, no, we don’t want that to happen to our dad. Dad, don’t do it. Doc, there must be something else you can do, like x-rays to melt the obstruction.”

The family members continue to converse among themselves, convinced that cutting a hole in their dad’s neck will certainly kill him. The father, struggling to breathe,

attempts to listen to their rationale. Without consent, there is not much to offer apart from elevating the head of his bed, providing oxygen, and close monitoring.

The following day, Mr. X requests to see me (Dr. Hage).

“Doc, please let them make the hole.”

The man is gasping for air while attempting to speak.

“It is me who cannot breathe, not them.”

He pauses to catch a breath.

“Doc, I want you to be there when they do it.”

That request is touching, showing trust and comfort by my presence, and should certainly be honored.

After the procedure his family members are in an optimistic mood noticing his improved breathing. Sadly, the man only lives for ten more days and then dies in his sleep. Although the actual cause of death is in no way related to the tracheotomy, the family feels let down and are validated by this “proof” of the procedure. The link between making a hole in the neck and imminent death is perpetuated.

Understanding the reasoning behind the refusal is important for patient management in this scenario. For this man and his family, there exists a deeply rooted belief that a hole in the neck equates to imminent death. This belief stems from observing others in the community who had to undergo this procedure, only to die shortly afterwards.¹⁵

As the physician I recognized that the tracheotomy was a means to prolonging life and was not curative. By taking this into account as well as the perspective of the family, I may have been able to explain the progression of the disease and rationale behind the procedure. The family could then have made an informed decision they felt comfortable with and appreciated the operation granting them an additional ten days with their father.

Story 2

A 36-year-old farmer intermittently used nasal decongestant sprays for years to alleviate congestion. Eventually, both nostrils became completely blocked prompting him to consult a specialist (Dr. Hage). Large polyps were visualized in both nasal passages. The polyps were surgically resected, and he was instructed to use nasal steroid sprays on a continuing basis for three months before returning for follow-up. Three years later, he returns with a recurrence of large nasal polyps causing bilateral blockage.

A revision operation is scheduled, but the procedure is postponed several times by the patient.

“Mr. Y, I noticed you postponed the operation twice and have requested a day on which I do not operate. Is there a reason you want that specific day?”

After some hesitation, he confides:

“Doc, you may not agree but I am a farmer and according to the McDonald Almanac my requested day would be the most favorable day to ensure the polyps would not return. The first operation was not successful because it was done in the wrong moon.”

The McDonald Almanac is an annual publication frequently utilized by Caribbean farmers containing meteorological data and information about the moon stages to determine optimal planting days.¹⁶ According to the patient, his previous operation was unsuccessful because it was performed on a date deemed unfavorable by the almanac for planting crops under the ground. Without delving further into the patient’s rationale for rescheduling and without knowledge of the local beliefs, a practitioner may have erroneously labeled this person a “difficult patient.” Understanding a patient’s narrative catalyzes a more successful physician-patient partnership.

Highlighting these stories within a narrative medicine framework can prompt medical students in training to begin to engage with cross-cultural difference so that effective care may be given to a patient. This is further illustrated by the writing of Dr. Saha et al. enumerating the importance of training physicians through the prism of narrative based medicine to acknowledge social health diversity and cultural influences. Through this mode of teaching, health care providers are able to “acknowledge and explore their own cultural influences...this process of critically questioning and deconstructing the “medicocentric” perspective was considered central to the ability to deliver effective care across cultural boundaries.”¹⁷

Story 3

A woman in her early forties sits next to my (Dr. Hage’s) desk holding a Vicks vapor rub in her hand. I can see an obvious swelling of the right cheek.

“What can I help you with today?”

“Doc, my sinuses are playing up. I can’t breathe through my nose and my teeth hurt.”

I let her talk, ask a few questions including if there is a history of diabetes mellitus ('sugar').

"Any problems with 'sugar'?"

"Not yet; it was okay last week."

All the time she has spoken as if something is affecting her speech but she is seemingly unconcerned by her altered speech pattern.

I cannot ignore the swelling of her cheek, the carefree impression of her mannerism, the complete lack of any hint given that it is troubling her. I must address that swelling in the face.

"So what about the swelling of your face I have noticed?"

"O, wait doc!"

At this point, she pulls a nutmeg from her mouth and with normal speech, apologizes. She places the nutmeg back in her mouth but this time on the opposite side. Intrigued by this scene I query her on the purpose of the nutmeg. She shyly explains that for the past few days she has had headaches. Blood pressure readings with her neighbor's machine were higher than normal.

"I don't like taking tablets and stopped the tablets for my blood pressure some weeks ago because the pressure was back to normal."

"So why the nutmeg?"

"Well my mother and grandmother say it lowers the blood pressure and prevents a stroke."

This lady illustrates two cultural phenomena intrinsic to the Caribbean. First, the patient's regard of diabetes mellitus (DM) as inevitable suggested by the response "not yet" when patients are asked about DM or elevated blood pressure.¹⁸ Most patients assume they will eventually suffer from one or both diseases due to the extremely high prevalence of both illnesses on the islands.^{15,19} Second, patients can have strong beliefs about the perceived cause of their medical problems and locally-sourced methods of cure and prevention. On Caribbean islands where nutmeg (*Myristica fragrans*) is a widely available crop, it has become a common practice to place it in the oral vestibule as a method of stroke prevention. This practice is rooted in a history where people with facial palsy placed hard objects in their mouth to prevent themselves from biting their cheeks. Due to the small size and smooth, oval shape of the nutmeg shell, it became the object of

choice. Over the years, the link between nutmeg and symptom relief shifted from post-palsy treatment to prevention of palsy. Old tradition thus passed down through generations taught that placing a nutmeg in the mouth would lower blood pressure and prevent stroke.

Blood pressure medication is often not taken as prescribed. Rather, it is often discontinued as soon as the pressure readings have lowered because patients believe that the medication has done its job.¹⁸ Headaches are often perceived as a recurrence of elevated pressure by patients. The nutmeg is then placed in the oral vestibule, sometimes in conjunction with resuming former prescribed blood pressure medications, when they fear they are at increased risk for stroke. Communicating with the patient why the antihypertensive medication needs to be continued even after symptoms are relieved and that it is okay to concurrently use the nutmeg as they please is important to build trust and medication compliance.

Story 4

A knock sounds on my (Dr. Hage's) step. In the small river village jungle where I live, this is the way to initiate medical attention outside clinical hours. An old man weathered by many years of sun exposure introduces himself as one of the few remaining pork-knockers (diamond and gold miners) in the area. He wants to show me something and has already pulled up his shirt. Distributed in a dermatomal pattern on the left side of his abdomen are dried vesicles and papules – a classic presentation of herpes zoster. Curiously, I visualize a blue dot by the center of his abdomen.

"Doc, that was pain! But much better now after the bonoeman (local healer) gave me bush tea to drink and some white pills." He looks me in the eye and says, "but I want your expert opinion!"

"Okay. Before I give you my opinion I'd like to know more about this blue dot I see there."

"Oh that dot! Well, the bonoeman said it would keep me alive in case the other side would start to show the same bumps."

"A great solution, I couldn't have done a better job myself!"

In some cultures it is customary to visit a local healer as a first course of treatment. As my visitor explains, the blue dot was placed by the village healer in an attempt to ward off death from this particular ailment. Through observing others who had fallen ill with this condition,

the healer must have noticed that if the person developed vesicles and papules on both sides of the body the chances of survival would diminish, and the person could die once the rash spread and met in the midline. To prevent the two sides from meeting, a healer would place a blue dot made of indigo, thus staving off death. Indigo is used because of its ties to mythical healing powers.²⁰ The white pills he received were most likely paracetamol, a cheap, readily available and frequently used medication in this area.

My expert opinion in this case was reassurance and praise for the treatment received. There was no need for an explanation about reactivated virus particles emerging from a dorsal root ganglion and speculation about the status of the immune system. I felt humbled in understanding the thought process that the bonoeman had derived on the merit of his observations, albeit not conforming to Western medicine established 'evidence based practice.'

Conclusion

Although the principles and practice of narrative medicine have been established as a field in medicine recently, narration itself, be it written or spoken, is not a new concept. Despite new advances in medicine, it is imperative to recall that the story told by a patient- the words they use, the facts portrayed, emotions conveyed, and their understanding of illness- are unique and as valuable as lab results and imaging. It falls to the physician to blend these various facets and facts to build shared understanding on the basis of evidence-based practice and the patient's narrative. The ability to formulate and relay findings, diagnosis, and treatment within the framework of a patient's story is often founded in years of clinical practice, social experience, and community engagement.²¹

A physician may consciously work toward excelling in the capacity of a caregiver by recognizing patient employment of abductive reasoning in order to understand the viewpoint of their patient. This mode of reasoning, basing causation on observations and pursuing theories to explain it, underpins the deductions described: a tracheostomy leads to death (Story 1), the farmers' almanac can provide positive outcomes by predicting the best day for surgery (Story 2), a nutmeg in the mouth can prevent stroke and decrease blood pressure (Story 3), and an indigo dot can stave off death from a rash (Story 4). These case reports reveal the importance for physicians and physicians in training to maintain an inquisitive and open mind when examining patients, as such observations can reveal a patients' beliefs about their medical problems that may compromise care. The art of medicine involves convincing the patient to believe in the pathogenesis of their illness and the consequent

treatment options without denigrating the patient's cultural beliefs, especially beliefs that are scientifically erroneous and perhaps detrimental to the patient's wellbeing. The ability to work within the context of a patient's cultural beliefs with life-improving, and perhaps lifesaving, medical knowledge is an important lesson for medical students to keep in mind as they progress with their training. By truly listening to and understanding the patient's story beyond a medicalized lens, the physician's capacity to build rapport with the patient increases along with the impact of care and healing in the clinical encounter.

Medical programs are now striving to instill the skills of communication pertaining to the concept of patient ideas, concerns, expectations (ICE) as the basis of the patient interview. Studies have shown that patient-based narrative in the form of ICE is associated with decreased medication prescriptions.²² Movements such as the implementation of ICE in medical education establishes a bridge to a shared patient-physician narrative by providing insight into the patient's goals and their underlying story that the physician can employ in clinical judgement making and care.

Despite all of our technological advances there should always be room for narrative medicine. Current medical practice in the face of the global COVID-19 pandemic has been heavily reliant on telemedicine to meet patient needs. Without the ability to draw labs or do a physical exam, this form of clinical practice is principally dependent on the patient's storytelling and the physician's ability to uncover the patient's "ideas, concerns, and expectations." This paradigm shift from conventional medicine to a more integrative approach utilizes the patient-centered storytelling inherent to narrative medicine promoting equity and inclusion. This enables the patient to be cared for as a whole individual rather than focusing solely on the disease with which they are presenting.

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