Sometimes Those Hoofbeats Are Zebras: A Narrative Analysis

Lori A. Roscoe

Narrative Inquiry in Bioethics, Volume 7, Number 1, Spring 2017, pp. 79-85
(Article)

Published by Johns Hopkins University Press
DOI: *https://doi.org/10.1353/nib.2017.0020*

CASE STUDY

Sometimes Those Hoofbeats Are Zebras: A Narrative Analysis

Lori A. Roscoe[‡*]

‡University of South Florida

*Correspondence concerning this article should be addressed to Lori A. Roscoe, University of South Florida—Communication, 4202 East Fowler Avenue, CIS 1040, Tampa, FL 33620–9951.

Email: lroscoe@usf.edu

Conflicts of Interest. The author reports no conflicts of interest.

Abstract. The case of BB, an 11-year-old girl who was hospitalized because of sudden odd seizure-like symptoms and catatonic affect, highlights several ethical issues and communication problems. The correct diagnosis was initially missed, partly because physicians are trained to think of the most common explanation for a patient's symptoms; the medical education truism "when you hear hoofbeats, think horses, not zebras" was not helpful in BB's case. The common habit of medical professionals to not revisit a diagnosis once one is established also led to missed opportunities to provide appropriate care for this young patient. The difficulty nurses and/or family members have in questioning a diagnosis and treatment plan are also discussed.

Keywords. Clinical Ethics, Ethical Focus, Case Study, Communication, Medical Error, Moral Distress, Two-Challenge Rule

Introduction

In difficult cases that present thorny ethical dilemmas as well as communication difficulties, it is sometimes tempting to be satisfied when things turn out pretty well, despite the great suffering involved. Such was the case described here, which came before the Ethics Committee of which I am a member. (I have obtained permission from the hospital administration to use the case as long as the patient's identity is concealed). This case was brought to the attention of the Ethics Committee for retrospective review by a charge nurse who was concerned about the high level of moral distress experienced by the nurses caring for this young patient. Most felt completely drained by the care they needed to provide, and were also frustrated that despite their best efforts, no improvement in the patient's condition seemed imminent. Addressing the moral distress experienced by nursing staff members was the primary theme of the committee's deliberations and reviews at the time this patient was admitted. Although this case eventually did have a positive outcome, much suffering was endured by the patient, her mother, and the nurses caring for her. We should not be satisfied with a "good enough" outcome. Those of us concerned with ethics in health care must remain cognizant of the principle of non-maleficence (first, do no harm) and remember that every step in the process must serve the dignity and value of the patients and health care providers involved.

Case study

BB, an 11-year-old girl, was enrolled in the fifth grade at her local elementary school. In late October, BB came home from school and said that she did not feel well. When her mother said that it was almost time to get ready for her dance class, BB seemed confused; instead of responding with her usual enthusiasm, she stared vacantly into space. Her mother noticed one of her legs twitching in a jerky manner. She hurriedly led BB to her car and took her to the nearest hospital Emergency Department (ED). Upon arrival, BB's mother explained her daughter's odd, "seizure-like" behavior and told the triage nurse that she was just "not acting right." Her mother described BB as an extremely bright child who could read at an eighth-grade level and who excelled in all subject areas. She said that it was highly unusual for BB not to want to attend her dance class, a favorite among her varied extracurricular activities. She told the triage nurse that with the exception of occasional mild asthma, BB had no significant past medical history. Upon examination, BB did show some odd twitching in her extremities, and did not appear to be the bright and enthusiastic child whom her mother had described. She had difficulty answering any direct questions or even making sustained eye contact with the ED physician, who ordered a full workup including electroencephalography (EEG) to record electrical activity of the brain; blood tests to measure electrolytes and monitor her endocrine system function, and to test for exposure to drugs; and a computed tomography (CT) head scan. Although BB continued to "not act right" in her mother's opinion, none of the tests found anything out of the ordinary. BB was discharged home with instructions to her mother to follow up with a pediatric neurologist if her daughter's "strange behavior" persisted.

ED physicians and triage nurses are accustomed to dealing with parents who are unwilling to disclose pertinent facts about their child's condition—such as exposure to illegal drugs, trauma, abuse, or other situations—that might make them appear to be unfit or neglectful. Although BB's mother did not appear to fit this stereotype, the ED physician and triage nurse agreed that the most likely explanation for BB's unusual behavior was some kind of psychiatric illness which would best be treated on an outpatient basis.

Back home, both mother and daughter had a restless night. BB continued to experience twitching and shaking of her arms and legs. She refused to eat or drink anything and appeared unable to understand anything that her mother said. She also refused to talk and only made moaning and gurgling sounds. By early morning BB was rambling and screaming, and attempted to hit and kick her mother while she helped her to get dressed. BB's mother took her back to the ED where she was admitted for further blood testing to screen for rare metal exposures, an array of known toxins, and infections. These additional tests, however, revealed no explanation for her behavioral changes. The attending physician told BB's mother that there was no apparent physiological cause for her daughter's unusual symptoms, and asked extensive questions about possible drug use, trauma, abuse, or any history of mental illness. BB's mother stated that there was no history of psychiatric distress nor had any traumatic events happened in their home, and she reminded the doctor that the drug screens had all come back negative. The attending physician told her that the most likely conclusion was that her daughter was suffering from a psychiatric illness and recommended that BB be transferred to the hospital's Behavioral Health Unit, which served as the inpatient psychiatric unit for both adults and children. BB's mother disagreed with this diagnosis but, absent another plausible course of action, did agree to the transfer.

BB's mysterious symptoms increased during her hospital stay. She rambled, stared, screamed, hit, kicked, twitched, and refused to eat or drink anything. She was alternately agitated and catatonic. There were periods during which she would turn to the wall and stare for hours on end, while her legs and arms became rigid and then flaccid. She refused to respond in any coherent way to either her mother or to the questions posed to her by the psychiatrist assigned to her case. The psychiatrist became convinced that BB was likely schizophrenic

and suggested starting her on some of the newer, second-generation antipsychotic medications approved by the U.S. Food and Drug Administration (FDA) in the late 2000s. When treating children, these second-generation medications are often tried first because they have fewer side effects compared with older antipsychotics. However, they can cause weight gain, high blood sugar, and high cholesterol, all of which were seen as longer-term side effects that might have to be addressed if the medications helped to stabilize BB's behavior and bring her apparent psychosis under control. She was started on a low dose of Zyprexa (Olanzapine), which was later supplemented by Seroquel (Quetiapine).

The medications had little effect on BB's behavior other than to make her a bit groggier, which was seen as an improvement by some of the nurses who were exhausted from taking care of her. BB still refused to eat or drink in sufficient quantities to maintain her nutritional status, and after a week she was transferred to the Children's Hospital for placement of a feeding tube. BB remained there for the next 46 days, where she required 24/7 1:1 staffing in order to prevent her harming herself or others. Despite an extremely thorough workup that included blood tests to help rule out conditions with similar symptoms (including the ingestion of alcohol or drugs), she again underwent imaging studies including magnetic resonance imaging (MRI) and CT head scans to look for abnormalities in the brain structure, as well as another EEG to look for abnormalities in brain function that might cause seizures.

Psychological evaluation was limited to observations of BB's appearance and demeanor, since asking about her thoughts and feelings resulted in either aggressive behavior or complete indifference. It was impossible to evaluate BB's mood or level of anxiety because of her behavior and inability or unwillingness to communicate with anyone. No explanation could be found for her psychotic behavior, nor was it really possible to evaluate how much of it was due to possible side effects from the antipsychotic medications. She slept, sometimes for hours at a time, then awoke with tense and trembling muscle spasms. She drooled, especially at night, and appeared to be gaining weight. Her eyes sometimes rolled up into her head, and her face appeared to lose its usual range of expression. She had become unrecognizable to her mother, who continued to visit every day to see her daughter and to ask over and over, "What more can be done for her?"

Caring for BB was a task that all of the nurses on the unit came to dread. They described her as "acting possessed," and they were afraid of her regular violent outbursts of kicking, hitting, spitting, poking, and pinching. The nurses and child life specialists tried music, touch, television, reading—nothing appeared to interest or comfort BB in the slightest. Her hallucinations, seizures, and loud outbursts of agonized moaning and indecipherable vocalizations alternated with catatonic behavior that, although worrisome, at least provided some respite from the intensive caregiving BB required in the more active phases of her psychosis. The charge nurse had to rotate the nurses carefully in order to avoid burnout, and at least three of them requested that they not be assigned to BB's care because of fears about their own safety and well-being. The attending physicians on the unit saw BB regularly, but were at a loss to determine an alternative cause for the drastic and unfortunate change in her behavior. Among themselves, the nurses had questioned whether BB's diagnosis was truly a psychiatric one, since at no time had a family history of trauma, abuse, or mental illness ever been discovered. At one point, the charge nurse asked BB's attending physician if indeed every possible diagnosis had been tested, but she was brusquely interrupted and informed that the nursing staff was to continue to provide 24/7 1:1 staffing to ensure BB's safety and care. The attending physician's direction to the nursing staff was to "stay the course" and wait for some combination of medications to stabilize BB's behavior.

Eventually BB was discharged in early December, along with home health nursing support and outpatient psychiatric services. The nurses on the pediatric unit were relieved that she had been discharged because the burden of providing care for her around the clock had severely tasked them.

BB's mother was overwhelmed by the continued dramatic and unexplained change in her daughter's behavior. She was frustrated that no satisfactory explanation could be found, nor was anything recommended that was likely to improve the ability of either her daughter or herself to function or enjoy any of the activities that had formerly enhanced their quality of life. She could not imagine how life could continue as it had over the last few months. She was not at all confident that she could manage to care for BB at home, even with professional assistance. She was now confronting the full extent of her daughter's needs, which had exhausted more than one nurse during her lengthy hospitalization.

BB was helped into her mother's car and they headed for home and the uncertainties ahead. On the drive home, she attempted to open the passenger-side door and jump from the moving car. Her mother changed her mind about heading home and instead went to another hospital's Emergency Department, hoping for another opinion. BB was admitted to this second hospital's adolescent medicine unit, where over the next 5 weeks she was again given a complete workup. The same tests were repeated and, again, no diagnosis was revealed. At this point BB's mother requested that her daughter be transferred to a third hospital, which was arranged.

Upon arrival at the third facility, BB was admitted and the hospitalist, Dr. S, took a detailed medical history. She then repeated all of the tests that BB had previously endured: EEGs, head CTs, extensive blood tests, and psychiatric evaluations. However, Dr. S added one additional blood test and a spinal tap, as she had recently learned about a rare autoimmune disease called anti-NMDAR (*N*-methyl-D-aspartate receptor) encephalitis. This disease was discovered in 2007, and predominantly affected children and young adults. Most patients with anti-NMDAR encephalitis developed a multistage illness that progressed from psychosis, memory deficits, seizures, and language disintegration into a state of unresponsiveness, abnormal movements, and breathing instability. This almost exactly conformed to the progression of BB's symptoms over the last several months. The blood and spinal fluid tests that Dr. S ordered would look for antibodies consistent with a diagnosis of anti-NMDAR encephalitis.

After several days, the test results were available and revealed the presence of antibodies consistent with a diagnosis of anti-NMDAR encephalitis. BB was immediately started on new medications, including corticosteroids and intravenous immunoglobulin, to reduce the level of antibodies in her blood and spinal fluid. Over the course of several weeks she slowly began to improve. Her hallucinations and unresponsiveness lessened, and she gradually regained language fluency and an appetite. The feeding tube was removed and BB could eat and drink normally. Upon her eventual discharge, her prognosis was favorable, although she would require close monitoring to catch any relapses, which occur in approximately 20% of patients. BB has returned to school, but her mother notes that she is more withdrawn and more tired than she was prior to her frightening and life-threatening illness.

Case analysis

This case highlights several ethical issues and communication problems, particularly medical education truisms such as "when you hear hoofbeats, think horses, not zebras," and the attendant habit of not revisiting a diagnosis once one is established. The difficulty nurses and/or family members have in questioning a diagnosis and treatment plan will also be discussed.

Most U.S. medical schools train their students to think of the most common and likely diagnosis rather than a more esoteric explanation of the symptoms they observe in patients. Dr. Theodore Woodward, professor at the University of Maryland School of Medicine, coined an aphorism in the late 1940s that instructed his students as follows: "When you hear hoofbeats, think of horses not zebras." "Zebra" is the American medical slang term for arriving at an exotic medical diagnosis when a commonplace explanation is more likely (Sotos, 2006). Horses are common in Maryland (and in most of the rest of the United States) and zebras are rare, so if one hears hoofbeats they are

more likely to be those of the former rather than the latter. By 1960, the aphorism was widely known in medical circles and remains an often-invoked lesson for medical students today (Imperato, 1979). This advice is helpful, especially to physicians with less experience, who might be predisposed to make rare diagnoses because events more easily remembered, like the exotic, are judged more probable when one has less experience to draw upon. This is referred to as the "availability heuristic," first described in the *Rhetorica ad Herennium* (circa 85 BC) as the idea that "the striking and the novel stay longer in the mind." The oldest surviving Latin book on rhetoric, *Rhetorica ad Herennium* is of unknown authorship but is usually attributed to either Cicero or an unnamed physician. As the case of BB cautions us, however, "zebra-type" diagnoses must also be held in mind as possibilities until the evidence conclusively rules them out.

Another diagnostic shortcut, Occam's Razor, reminds clinicians that the simplest explanation is usually the correct one. Parsimony is valued in medicine, and if one explanation adequately covers a patient's symptoms it is usually presumed to be correct. Medical education teaches doctors-in-training to evaluate a patient's symptoms and create a differential diagnosis, or list of diagnostic possibilities. The most likely or common diagnosis then indicates which tests should be ordered and which treatments are likely to be appropriate. In BB's case, since routine blood tests and imaging studies failed to reveal anything "zebra-like" or complex, they appeared to rule out an exotic diagnosis.

Other research, largely based on Emergency Departments, highlights the difficulty of revising a diagnosis once it has become attached to a patient's situation. Eisenberg and colleagues (2005) revealed how resistant to change a diagnosis can be once it has been recorded in the patient's chart or electronic medical record and agreed upon by those present at the initial intake. This resistance to evaluating new data, whether in the form of background information provided by the patient or his/her family as part of the patient's "story," or of additional test results that do not confirm the original diagnosis, can lead to patient safety errors and untold hours, weeks, or months of needless uncertainty and suffering. BB appeared to be a schizophrenic or at least a psychotic adolescent, and despite the fact that neither her test results nor medical history revealed any likely reasons for a psychiatric illness, this label was consistently applied to her condition. Eisenberg and colleagues observed that a better recognition of uncertainty in emergency medicine communication is an important first step in anticipating potential failures [of diagnosis] and ensuring patient safety (2005). BB's mother did alert the Emergency Department physician and attending physician to the fact that there had been no trauma, no abuse, and no history of psychiatric illness in either BB or her family, but her agreeing to transfer her daughter to a psychiatric inpatient unit also might have lent credence to the label of mental illness as an explanation of her daughter's dramatic behavioral change.

Another study of emergency medicine revealed the limited value placed on a patient's medical history or story (Roscoe, Eisenberg, & Ford, 2016). Triage nurses are more likely to trust their visual impressions of a patient and vital signs and other test results when making an initial diagnosis or evaluation of patient acuity. The patient's story is accorded much less validity than what triage nurses could observe or measure. The nurses in this study were much more likely to rely on visual signs (skin pallor, aggressiveness, communication fluency) and vital signs and other test results than on a patient's or family member's explanation of why they were in the ED or their offering of a complete medical history. "Patients lie" was a consistent refrain when nurses in this study were asked about patients' stories. In BB's case, it was quite plausible to the medical staff that her mother would deny any substance abuse, trauma, or previous psychiatric symptomatology in order to protect her daughter and herself. Unfortunately, while true, her narrative was not compelling enough to counteract the evidence of BB's psychotic behavior and the subsequent diagnosis of a psychiatric illness.

The other notable communication problem in this case was the inability of the nursing staff members to question the diagnosis and to insist on further testing to more definitively confirm

a psychiatric illness. The nurses caring for BB experienced a high level of moral distress, which occurs when the ethically appropriate course of action is known but cannot be taken because of institutional structure or conflicts with coworkers (Elpern, Covert, & Kleinpell, 2005; Jameton, 1993). Moral distress can adversely affect job satisfaction, retention, and physical and psychological well-being (Elpern et al., 2005). BB's mother's attempts to explore alternative explanations for her daughter's behavior were ultimately successful. It was easier for her to transport BB to multiple hospital Emergency Departments than to question the diagnosis that essentially kept her, her daughter, and the nursing staff in purgatory for several nearly intolerable months. Medicine is a hierarchical business, and physicians are the unquestioned leaders. Despite the fact that nurses spend much more time at a patient's bedside than do doctors, and that most parents have a life-long history with their children, physicians still write the orders that dictate patient care, and are the ones in charge of determining a diagnosis and a course of treatment. In BB's case, the intractability of her symptoms and her unresponsiveness to antipsychotic medications should have triggered a renewed search for an alternative diagnosis, especially since the nurses charged with her daily care reported increasing levels of distress and burnout.

It is so difficult for nurses (and residents) to question physician authority that a communication tactic called "the two-challenge rule" has been implemented to try to insure that nurses, residents, and other nonphysicians can question physician authority—not once, but twice—in order to better insure patient safety and to garner the benefits of multidisciplinary teamwork (Pian-Smith et al., 2009). The two-challenge rule is a communication technique taught to nurses and other nonphysician medical providers that teaches them how to speak up as patient advocates. It is designed to allow anyone to question any aspect of a patient's situation and to call a momentary halt to the proceedings in order to allow new information to better inform patient care and prevent patient safety errors. This protocol specifies that nurses and others should have two essentially "free passes" to question the status quo without suffering adverse consequences, and asks all involved in direct patient care to value the contributions of all members of the medical care team and to address communication barriers between practitioners at different levels.

The two-challenge rule has been studied largely through simulation, likely because of the rarity of instances in which nurses and others of lower status effectively challenge physician authority (Pian-Smith et al., 2009). Degeling, Kennedy, and Hill (2001) studied cultural boundaries between medicine, nursing, and hospital management, and found that nurse clinicians were critical of the "differential power relations that characterize a hospital and were keenly aware of the risks and uncertainties that were posed for them (personally) should they question these" (p. 38). Consistent with their relatively low assessments of their power, nurses tended to prefer employment security over personal autonomy, and to defer to custom and precedent, including the traditional authority of physicians, rather than to their own rationality and observations.

BB's case had a relatively happy ending. After many trying weeks and months of inexplicable behavior change, unhelpful medication regimens, and high levels of caregiver angst and burnout, she was given a correct diagnosis—a "zebra-diagnosis," as it were—that provided a clear and helpful treatment regimen and a defined way forward. So many factors worked against this positive outcome: insurance prohibitions that limit physicians' willingness to order nonstandard bloodwork and other tests; medical education that warns new physicians against diagnosing "zebras"; the tendency to stay the course once a likely diagnosis has been determined; and status and communication barriers that prevent nurses, family members, and others from insisting that alternative explanations be explored. Thankfully, BB is on the road to recovery, but so much misplaced effort, anxiety, and turmoil could have been avoided if only we could see the wisdom of questioning our assumptions, talking to one another, and thoroughly taking a patient's story into consideration.

Reflection Questions

1. Hospitals are generally reluctant to admit patients known to have problematic behavior or unknown diagnoses, yet in this case, having a new physician on her case was the key to making an accurate diagnosis. How might transfers between medical facilities be reimagined to improve patient care, rather than being seen as "dumping" of undesirable problematic patients and families?

2. What interventions or changes in protocol might empower nurses and family members to productively question a physician's diagnosis and treatment plan for a patient?

References

Degeling, P., Kennedy, J., & Hill, M. (2001). Mediating the cultural boundaries between medicine, nursing and management—The central challenge in hospital reform. *Health Service Management Research, 14* (1), 36–48.

Eisenberg, E. M., Murphy, A. G., Sutcliffe, K, Wears, R., Schenkel, S., Perry, S., & Vanderhoef, M. (2005). Communication in emergency medicine: Implications for patient safety. *Communication Monographs, 72*, 390–413.

Elpern, E. H., Covert, B., & Kleinpell, R. (2005). Moral distress of staff nurses in a medical intensive care unit. *American Journal of Critical Care, 14* (6), 523–530.

Imperato, P. J. (1979). *Medical Detective*. New York, NY: Richard Marek.

Jameton, A. (1993). Dilemmas of moral distress: Moral responsibility and nursing practice. *AWHONN's Clinical Issues in Perinatal and Women's Health Nursing, 4* (4), 542–551.

Pian-Smith, M. C., Simon, R., Minehart, R. D., Podraza, M., Rudolph, J., Walzer, T., & Raemer, D. (2009). Teaching residents the two-challenge rule: A simulation-based approach to improve education and patient safety. *Simulation in Healthcare: Journal of the Society for Simulation in Healthcare, 4* (2), 84–91.

Roscoe, L. A., Eisenberg, E. M., & Forde, C. (2016). The role of patients' stories in emergency medicine triage. *Health Communication*. Retrieved from http://www.tandfonline.com/doi/full/10.1080/10410236.2015.1046020

Sotos, John G. (2006). *Zebra cards: An aid to obscure diagnoses*. Mt. Vernon, VA: Mt. Vernon Book Systems.