SECTION I

Patient Care

Healthcare professionals must be able to demonstrate the provision of patient-centered care that is compassionate, appropriate, and effective for the treatment of health problems and the promotion of health. Specific competencies within the Patient Care domain are to:

- Perform medical, diagnostic, and surgical procedures considered essential for the area of practice.
- Gather essential and accurate information about patients and their conditions through history-taking, physical examination, and the use of laboratory data, imaging, and other tests.
- Organize and prioritize responsibilities to provide care that is safe, effective, and efficient.
- Interpret laboratory data, imaging studies, and other tests required for the area of practice.
- Make informed decisions about diagnostic and therapeutic interventions based on patient information and preferences, up-to-date scientific evidence, and clinical judgment.
- Develop and carry out patient management plans.
- Counsel and educate patients and their families and empower them to participate in their care and enable shared decision making.

- Provide appropriate referral of patients, including ensuring continuity of care throughout transitions between providers or settings, and following up on patient progress and outcomes.
- Provide healthcare services to patients, families, and communities aimed at preventing health problems and maintaining health.
- Provide appropriate role modeling.
- Perform supervisory responsibilities commensurate with one's roles, abilities, and qualifications.

The four cases presented in Section 1 represent a range of events, types of patients, and care settings that illustrate and demonstrate key elements of the Patient Care domain. The cases are complex and include elements of other competency domains as well. As you read the cases, think about the other competencies that are relevant. (Refer to the full list of competencies in the appendix.)

The first case relates to Lewis Blackman's postoperative death following an elective surgery at an academic medical center hospital in the United States. Lewis was 15 years old when he underwent surgery for a congenital abnormality, pectus excavatum. Case 1, "It's Hard to Kill a Healthy 15-Year-Old," was the impetus for this book of case studies.

Case 2, "Routine Appendectomy," is set in Perth, Australia. Sandra Pintabona, a nurse, shares the tragic story of her husband's surgery and postoperative complications. Now, more than a decade later, John has never fully recovered from these events. Sandra Pintabona writes about her challenges as a senior healthcare professional in navigating the healthcare system to get the best care for her husband.

Julie Bailey wrote Case 3, "The Origins of the Mid Staffordshire Inquiry into the National Health Service," about her mother's death at the Mid Staffordshire Hospital in the United Kingdom. Bella Bailey was admitted to the hospital with a hiatal hernia. Julie's

observation of the substandard care of her mother and other inpatients ultimately led to the Mid Staffordshire Inquiry—the largest inquiry of its kind, commissioned in 2010 to examine the care provided by the UK's National Health Service (NHS).

The final case in this section, Case 4, is about the death of James Mannix in the United States. In the summer of 2001, Mary Ellen and Michael Mannix learned from a prenatal echocardiogram that their fourth child, James, had a high chance of being born with a heart defect. In Case 4, "Consent and Disclosure in Pediatric Heart Surgery," Mary Ellen Mannix writes about James's death just days after birth due to a series of medical errors and system failures.

CASE 1

It's Hard to Kill a Healthy 15-Year-Old

The Story of Lewis Blackman (United States)

Helen Haskell, Julie Johnson, and Paul Barach

Editors' Note

Lewis Blackman was born with pectus excavatum, which literally means "hollowed chest." It is a congenital abnormality of the anterior wall of the chest that results in abnormal growth of the sternum and the adjoining sections of ribs. Whereas mild cases may only result in a sunken appearance of the chest, more severe cases may be associated with impaired cardiac and respiratory function (Crump, 1992; Shamberger, 1996). Many people with pectus excavatum also suffer from negative body image and self-esteem (Medline, 2007), and patients may seek surgical correction for either physical or psychological reasons. In the United States, pectus excavatum is thought to occur in about 1 in 300 to 400 white male births, with a male-to-female ratio of approximately 5:1. Although data are limited, there is reason to believe that the international incidence is approximately the same in most populations. The defect appears to be rare in persons of African descent (Jaroszewski et al., 2010).

Lewis underwent surgery for his pectus condition at age 15. He died 4 days later, without ever having left the hospital. Helen Haskell, Lewis's mother, tells the story of the events surrounding her son's surgery and death. Since Lewis's death, Helen has worked on patient safety issues in the United States and internationally by organizing parents and medical error victims into a mutual support group, Mothers Against Medical Error.

LEARNING OBJECTIVES

After completing this case study, you will be able to:

1. Outline the elements of an effective informed consent process.
2. Hypothesize the effect of professional hierarchy on communication patterns, patient care, and patient safety.
3. Evaluate the causes of failure to recognize and act upon acute deterioration in patients.
4. Discuss the elements of the Lewis Blackman Patient Safety Act as an example of the patient perspective on communication problems in hospitals.

The Decision to Operate

Taking Lewis for the pectus surgery was not an easy decision. His pectus defect, although noticeable, was relatively mild and did not cause any obvious problems. An easygoing boy, Lewis was an avid soccer player who had no evident impairment in stamina, and he was not particularly self-conscious about the concavity in his chest. He was also a high-achieving ninth-grader with a busy schedule from which he was not eager to take time out. We had never considered seeking surgical correction until we saw a newspaper article promoting a new, minimally invasive surgery that was supposed to be safer and quicker than the older method of opening the chest and remodeling the ribs and cartilage. We discussed the options with our family physician and made an appointment with a surgeon. The evidence presented by the surgeon was limited, but we decided to go ahead with the minimally invasive surgery because we were told that the procedure would become more difficult as Lewis got older. The operation was to be performed at a leading academic medical center several hours from our home. The entire family—Lewis, his younger sister, my husband, and I—spent the night in a hotel and arrived at the hospital on a Thursday morning for the surgery.

At the Hospital

Upon arrival at the hospital, we were surrounded by activity as nurses and residents took Lewis's vital signs, filled out forms, and

asked us to sign documents. One of the documents, not particularly emphasized, was a one-paragraph consent form for the surgery. By 7:00 a.m., Lewis had been whisked away to surgery. When the surgeon came out later, he told us the operation had gone well, but it took longer than we expected—2 and a half hours instead of the anticipated 45 minutes. (**Figure 1-1** uses process mapping to summarize the tragic series of events that transpired over the next 4 days leading to Lewis's death.)

The first sign we had of a potential problem occurred in the recovery room, when the nurse told us that Lewis was producing abnormally low amounts of urine. In spite of this, he was prescribed a standard 5-day adult dose of the intravenous nonsteroidal anti-inflammatory (NSAID) painkiller ketorolac (trade name: Toradol). This medication should be used with caution in patients with low fluid output and was not approved for use in children younger than 16. Nevertheless, Lewis's condition appeared to be generally stable for the first 3 days in the hospital. But on Sunday, the morning of the fourth postoperative day, half an hour after a ketorolac injection Lewis was suddenly overcome by severe pain in the upper abdomen. Nurses and a medical intern were initially concerned, but then assured us that he was suffering from postoperative constipation that would resolve if he got out of bed and began moving around. However, his condition continued to worsen, and his vital signs began to deteriorate in an alarming way. Here is a quote from my journal describing what happened later that day:

It is now afternoon. Lewis's bowels and urinary system are still not functioning. His belly is hard and distended and he is extremely pale, with a subnormal temperature and a constant cold sweat. His eyes are sunken and surrounded by huge black circles. Lewis is exhausted and in agony. His pain is now radiating to the shoulder. He is also nauseated and often burps, a new symptom. He still tries not to throw up, because he has been told the fruit juice he has drunk will help revitalize his digestive system.

We call the nurse a number of times. She seems to be convinced that Lewis is simply lazy and not walking enough to dissipate his "gas pain." Sometimes no

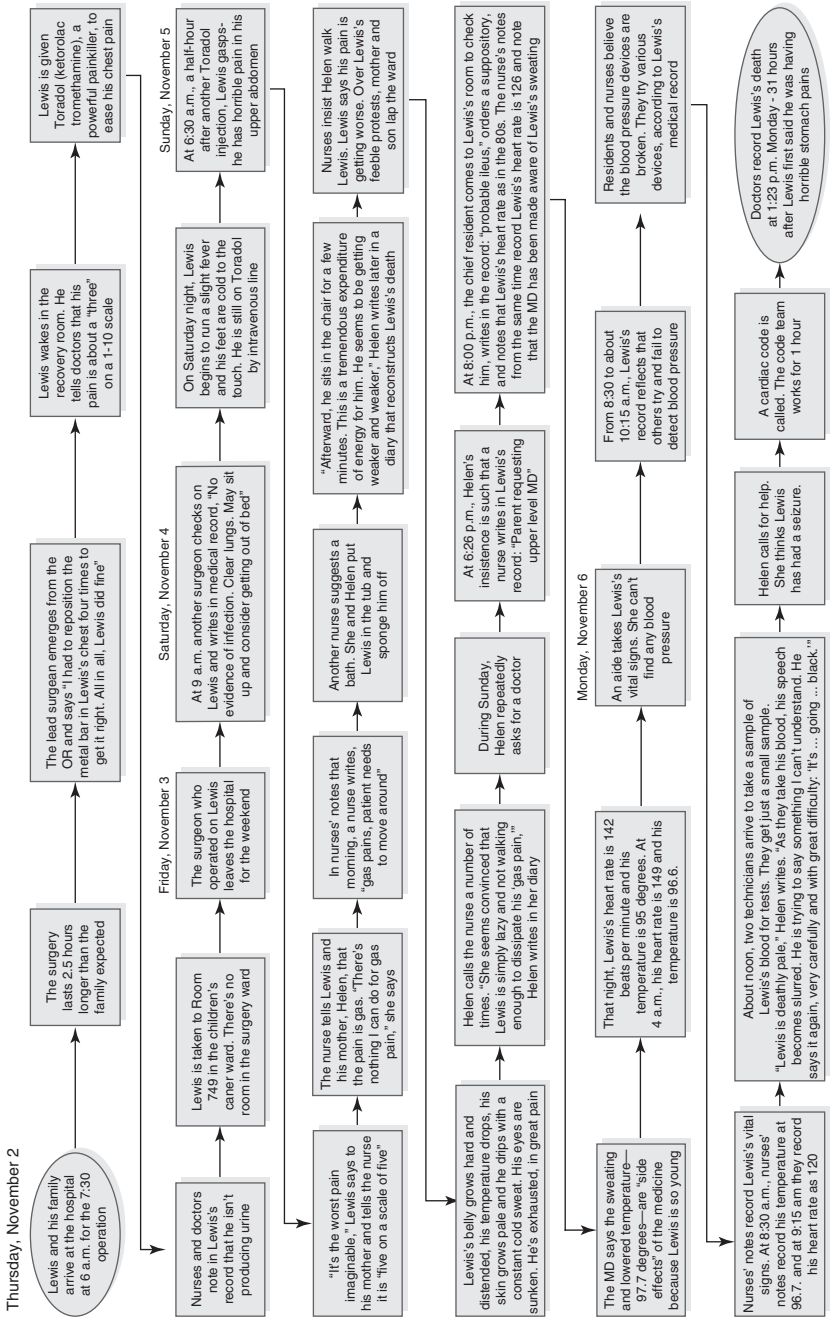

Figure 1-1. Lewis's Story

Johnson, J.; Haskell, H; Barach, P. "The Lewis Blackman Hospital Patient Safety Act: It's Hard To Kill A Healthy 15-Year-Old." McLaughlin, C; Johnson, J.; Sollecito, W (Editors). "Implementing Continuous Quality Improvement in Health Care: A Global Casebook." Jones and Bartlett Learning, 2012.

one answers my call. Other times the receptionist answers with weary exasperation, making it clear they consider our concerns a nuisance. They are busy, using this Sunday to spruce up the ward in preparation for a Joint Commission survey scheduled for the next day. The receptionist is painting decorations on the windows. Another nurse is updating the plates on the doors, including ours. When I go into the kitchen, I find someone has rearranged all the silverware and condiments and stacked them all in new plastic bins. For much of the afternoon, as I hunch over the bed with Lewis gripping my hand in pain, I can hear the nurses chattering and laughing in the break room.

Although we did not realize it, there was no attending or senior resident surgeon present in the hospital on Sunday because of low weekend staffing. Our requests for a senior physician in the face of Lewis's increasing pain and weakness met with resistance from the nurses, who did not seem to want to call. When a doctor finally came, he was not the attending physician, but a senior surgical resident who never identified himself as such. Here is another quote from my journal:

Someone calls a doctor. I assume at the time that this is the attending physician I have requested, though I later learn he is a fourth-year general surgery resident. It is some time before he arrives and when he does he is clearly coming in from outside, wearing a jacket and bringing with him a whiff of cold air. Apparently the intern is the only pediatric surgeon on duty in the hospital. And somewhere along the line my request for an attending physician has been quietly shelved. I do not know who made this decision.

The doctor is reassuring. He also thinks Lewis's pain is gas pain due to lack of motility in the intestine. Because Lewis has still not urinated, the doctor does an "in-out" urinary catheterization, thinking that this will relieve some of the pressure on the bowel. The catheterization produces a relatively small amount (c. 215 cc) of dark, concentrated urine. The doctor is a little surprised: he thinks a full bladder should have produced more urine. [Lewis had not urinated for nearly 12 hours.] I ask him about the pallor, the cold sweat, and the subnormal temperature. He says these are side effects of the medication, because Lewis is so young and "pristine." I wonder why they do not change the medication if it has such terrible side effects.

The doctor ordered a blood test (a metabolic panel) but critically, as we later learned, he omitted the complete blood count that might

have shown infection or bleeding. When the test results came back, the nurse told us they showed an elevated potassium level but that it was nothing to worry about. What she did not say was that there were a number of other slightly aberrant values that, taken all together, might paint a concerning picture in a healthy young post-operative patient.

We were still worried, but we did not know what else to do. We thought we had seen the attending physician and had gone as high as we could go to address our concerns. Technicians routinely continued to record Lewis's increasingly unstable vital signs every 4 hours. There was no further assessment or intervention. But when the vital signs technician came at 8 a.m. the next morning, she was unable to get a blood pressure reading. The intern went to the operating room to ask what to do. When she came back, as we watched in increasing fear, she and the nurses spent over 2 hours trying to find a blood pressure device that would work. In all, they took Lewis's blood pressure 12 different times with seven different blood pressure cuffs and machines. At noon, shortly after another ketorolac injection, Lewis went into cardiac arrest as phlebotomists tried to draw blood for a second metabolic panel. After a slight delay, a cardiac arrest code was called. Lewis was declared dead about an hour and a half later. Again, my journal recounts the details:

We were asked to leave the room and wait in the hall. Someone comes to get us. The doctors want to talk to us. I am fearful they will tell us Lewis is brain-damaged. When we go into the room, there are five surgeons in green scrubs. One introduces himself as Dr. Adamson. He is the doctor on call. We have never seen him before. Dr. Adamson says, "We lost him." This makes no sense to me. He is speaking as though Lewis has lost a battle with a long illness. He has to repeat it several times before I understand.

The physicians told us that they did not know why Lewis died. They said their chief resident had found nothing wrong the night before. This was the first we knew that the doctor who had come the night before had not been the attending physician we had requested.

Conclusion

A month after Lewis's death, we journeyed back to the hospital to meet with the surgeon who had performed Lewis's surgery. The surgeon listened to our story with compassion; he apologized and accepted responsibility for Lewis's death. We have always admired his courage in doing this.

The hospital later settled with us without a lawsuit. A physician friend with whom we had consulted was not surprised. "It's hard to kill a healthy 15-year-old," he said. A year and a half later the attending physicians involved in Lewis's care coauthored an institutional study comparing complications of the minimally invasive surgical procedure Lewis had with the open-chest procedure that it was in the process of replacing. The study, a retrospective chart review of 116 patients having the procedure in two institutions, was terminated a few weeks before the date of Lewis's surgery and reported "no deaths" among the surgical patients (Fonkalsrud et al., 2002).

It became our mission to try to find out what had happened to take our vibrant, exuberant boy from robust health to death in just 4 days. We spent months, in some cases years, trying to follow all the threads in our son's case. When we put it all together, we realized that our son was the victim of a profoundly dysfunctional medical system. We had thought we were sophisticated consumers, but we gradually realized that we had sacrificed our firstborn child to a system whose dangers we had almost no way of knowing. The system had not malfunctioned. It was simply not designed to respond in a timely fashion to an in-hospital emergency.

Case Discussion

The tragic and needless death of Lewis Blackman can be understood in the context of errors in decision making (Acquaviva, K., Haskell, H., Johnson 2013). The autopsy identified the cause of Lewis's death as an undiagnosed perforated giant duodenal ulcer, of a type often associated with NSAIDs (Collen & Chen, 1995). As a result of the

perforation, Lewis had developed peritonitis and had lost more than half his blood into his peritoneal cavity.

Lewis's parents blamed the devastating outcome on the confusion and poor communication of the teaching hospital hierarchy, and particularly on their inability to determine which caregivers were fully trained professionals and which were clinical trainees. In addition, the problem was exacerbated by lack of supervision and inability of the professionals-in-training to diagnose the real problem and intervene to save their son. No fully trained surgeon saw Lewis in the 2 days before he died.

The fatal cascade of events outlined in Lewis's case led to a legislative requirement requested by the patient advocacy group Mothers Against Medical Error (MAME). MAME worked with South Carolina hospitals to pass the Lewis Blackman Hospital Patient Safety Act. This state law requires that hospital personnel wear badges that indicate their jobs and professional status, that hospitals give patients information on the role of residents and students in their care, that patients be allowed to contact their attending physicians directly, and, that hospitals give patients and families a means of calling for immediate help in urgent medical situations. The intent of the South Carolina Department of Health and Environmental Control to enforce the law through inspection is outlined in the memorandum shown in **Exhibit 1-1**.

Subsequently, the state of South Carolina endowed the Lewis Blackman Chair of Clinical Effectiveness and Patient Safety as a testament to Lewis's remarkable young life and as a commitment to advance the health and safety of all South Carolinians. Nine simulation clinics have been established across the state for training healthcare providers in the teamwork techniques needed for dealing with emergency situations. These simulation clinics use team training exercises and sophisticated simulation technology with high-end full-body adult and infant mannequins to simulate patients with various clinical scenarios. A plaque dedicated to Lewis is featured in each of the simulation clinics.

Exhibit 1-1 Overview of Lewis Blackman Hospital Patient Safety Act

The Lewis Blackman Hospital Patient Safety Act (Article 27, Section 44-7-3410 et. seq.) was added to the SC Code of Laws, effective June 8, 2005. The act authorized the South Carolina Department of Health and Environmental Control (DHEC) to implement and enforce the provisions of the act, which requires hospitals to, among other things:

1. Identify all clinical staff, clinical trainees, medical students, interns, and resident physicians (as defined in the Act) as such with identification badges that include their names, their departments, and their job or trainee titles. All the above must be clearly visible and explicitly identified as such on their badges and must be stated in terms or abbreviations reasonably understandable;
2. Institute a procedure whereby a patient may request that a nurse call his or her attending physician (as defined in the Act) regarding the patient's personal medical care. If so requested, the nurse shall place the call and notify the physician and or his or her designee of the patient's concerns. If the patient is able to communicate with and desires to call his or her attending physician or designee (as defined in the Act), upon the patient's request, the nurse must provide the patient with the telephone number and assist the patient in placing the call;
3. Provide a mechanism available at all times, and the method for accessing it, through which a patient may access prompt assistance for the resolution of the patient's personal medical care concerns. "Mechanism" means telephone number, beeper number, or other means of allowing a patient to independently access the patient assistance system. If a patient needs assistance, a clinical staff member or clinical trainee (as defined in the Act) must assist the patient in accessing the mechanism;
4. Establish procedures for the implementation of the mechanism providing for initiation of contact with administrative or supervisory clinical staff who shall promptly assess the urgent patient care concern and cause the patient care concern to be addressed.
5. Provide to each patient prior to, or at the time of the patient's admission to the hospital for inpatient care or outpatient surgery, written information describing the general role of clinical trainees, medical students, interns, and resident physicians in patient care. This information must also:
   a. State whether medical students, interns, or resident physicians may be participating in a patient's care, may be making treatment decisions for the patient, or may be participating in or performing, in whole or in part, any surgery on the patient.
   b. Notify the patient that the attending physician is the person responsible for the patient's care while the patient is in the hospital and that the patient's attending physician may change during the patient's hospitalization.
   c. Include a description of the mechanism (see above) providing for initiation of contact with administrative or supervisory clinical staff and the method for accessing it.

Johnson, J.; Haskell, H; Barach, P. "The Lewis Blackman Hospital Patient Safety Act: It's Hard To Kill A Healthy 15-Year-Old." McLaughlin, C; Johnson, J.; Sollecito, W (Editors). "Implementing Continuous Quality Improvement in Health Care: A Global Casebook." Jones and Bartlett Learning, 2012.

Questions

1. Where did the system fail Lewis and his family?
2. Where in the process of care did incidents (errors, near misses, adverse events, and harm) occur?

3. What would be the elements of a more transparent informed consent process?
4. What aspects of this incident will the legislation cited in the case address? Which aspects does it not address, and what else should be done to prevent similar incidents?
5. What can we learn from this case in designing strategies and/or tools to engage patients and families?
6. Which of the core competencies for health professions are most relevant for this case? Why?

References

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Additional Recommended Readings

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