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Are We Practicing What We Are Taught in Health Professions' Education? Coproducing Health Care

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empathy, patient engagement, patient perspectives/narratives, patient expectations

Introduction

Health-care providers and educators are inherently empathetic, compassionate, experienced professionals who entered their profession to assure the complementary missions of public health and health care. These missions work to ensure conditions in which people can be healthy via disease and injury prevention, health promotion, and timely, effective, coordinated care (1). The skills necessary to achieve these crucial outcomes (ie, listening to the patient and their family, exhibiting empathy, and understanding the significance of the social determinants of health, etc) are routinely taught in health professions' education.

To highlight the necessity for these representative competencies covered throughout the course of health professions' education, the personal experience of one of the author's children is reported as a narration. The purpose of communicating this patient experience is to remind health-care providers: (a) about the importance of not only listening but hearing the parents of our patients and the patients themselves, (b) to actively practice the art and skill of empathy as the health-care setting can be overwhelming for patients and their families, and (c) to consider the impact of the social determinants of health on one's health status to date. This 5-part patient experience serves to strengthen our commitment to assure that we practice what we are taught with the goal to coproduce health with our patients and their families.

Patient Experience

Misdiagnosis

My normally healthy 15-year-old daughter woke up in the early morning hours of April 26, 2017 at her home in Manchester, New Hampshire, United States of America with a severe stomachache and nausea. I returned her to bed with

a heating pad to place on her stomach once the nausea subsided. An hour later, she appeared at my bedside with the same complaint. I repeated the steps we had taken earlier. A few minutes after settling her, she screamed in pain and I ran into her room. She was very pale and reported that this was the worst pain she had ever experienced. At this point, knowing we were dealing with something potentially serious, I helped her dress and drove to the Urgent Care Center affiliated with our local hospital. She almost fainted on our walk into the facility. Following an examination, the physician's assistant surmised that the pain could be caused by an inflamed appendix, so I was directed to transport her to the emergency department (ED) immediately.

By the time my daughter was admitted to the ED a short while later, the pain had migrated to both the lower left and right abdominal quadrants. Lab work indicated an elevated white blood cell count, which led to a subsequent pelvic examination and ultrasound, the thought being that perhaps an ovarian cyst may have ruptured. After completion of these additional tests, a pediatric surgeon was consulted, confirmed the findings, and was preparing to discharge her. As I was holding her, awaiting discharge, I noticed she felt very warm, which was a new symptom. After a temperature check confirmed my suspicions of a pending fever, I informed the attending ED physician that I would not be taking my daughter home. I wanted her admitted to the hospital.

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Through the night, Tylenol was administered to reduce the fever. Every time it wore off, her temperature spiked. The next day, an ultrasound was done to view the appendix. This visual aid proved fruitless so in the afternoon, I was presented with the option to have an MRI done. The Magnetic Resonance Image (MRI) showed a ruptured appendix. My daughter underwent surgery immediately and was kept in the hospital for a week and treated with antibiotics.

Late Night Move

Toward the end of her hospital stay, my daughter who had earlier in the week been moved to a patient room with monitors due to a sudden drop in blood pressure postoperatively, and I were suddenly woken in the middle of the night by a pediatric nurse who ran into the room telling us we needed to vacate the room immediately for another child who was being admitted. She and another nurse started hastily moving our belongings, as I helped to move my daughter. As soon as we were settled in the new room, my daughter began to cry. Thinking she was in pain, I called the nurses who had abruptly relocated us, and they asked why my daughter was crying. My daughter quietly replied that there was no rocking chair in the new space, as there was in the previous room, so this meant her grandmother could not come and visit, a fact that, in the hurriedness of the move, was overlooked.

Late Diagnosis

Our journey continued through the summer when my daughter complained of abdominal discomfort and painful urination despite several negative results for a urinary tract infection. I brought her in to see our pediatrician for 3 visits: once a week for 3 weeks due to her discomfort. Her pain continued to escalate with each visit, eventually radiating to her lower back on the right side. At the third visit, with no break in pain, I requested a Computed Tomography Scan (CT) scan of her abdomen, so we could have a visual of what might be causing her such discomfort. The pediatrician refused to order a CT scan based on the radiation dose and told us that it was likely a gastrointestinal illness.

The following morning, my daughter woke up with the same pain, but it had now radiated to the lower left side of her back. Since there was no improvement in her overall condition, I took her to the ED where, upon examination, her vital signs and lab work appeared normal. As the ED physician was getting ready to discharge her, I told him I was not bringing my daughter home due to her increasing pain level and overall pallor. Fortunately, the pediatric surgeon who performed the appendectomy was on call, so the ED physician consulted with her and a CT scan was ordered. The scan indicated an unusual mass in her lower abdomen and an exploratory laparoscopy was done. Both the mass and intensifying pain were identified as adhesions

that had formed around the bladder as a result of her initial appendectomy.

Misdiagnosis Again

Several weeks following this second surgery, my daughter was still not feeling well. She had been experiencing severe headaches with photosensitivity. I brought her to the weekend pediatrician practice affiliated with our local hospital where she tested negative for flu. She was prescribed an antibiotic and treated for a sinus infection. Two days later, she experienced vertigo, became disoriented, almost fainted, and complained of a severe headache that was not localized to her sinuses. I brought her to the ED and I requested a comprehensive blood panel be ordered to which my daughter tested positive for Epstein-Barr Virus and was instructed to stop taking the antibiotic immediately.

Social Labels

Throughout the subsequent months, my daughter continued to experience abdominal discomfort. Seeking a specialist who might be able to provide additional insight into her care, we were referred to a local gastroenterologist. During our first encounter, my daughter was wearing my old Harvard sweatshirt, and this was the first thing the specialist noted after introducing himself. He asked if that was where my daughter wanted to go to school and she said, "No, that is where my Mom went to school." In one sentence, there was a palpable shift in our encounter. We were not rushed, and I was treated differently than I had been on any previous interaction with our health-care system.

Discussion

During this patient experience, the author's training as a health professions' educator was piqued, as she found herself having to advocate for her daughter throughout every step of the diagnosis and recovery process. After her daughter had successfully made it through her appendectomy, the pediatric surgeon commented that the author had been a strong advocate for her daughter. The pediatric surgeon had been ready to discharge her due to the fact that the patient did not present as a "classic textbook" case. Additionally, the patient's quietness throughout her hospital stay was interpreted as stoicism, instead of being attributed to its true cause. The author served as her daughter's voice and was cognizant of facilitating open communication to her health-care providers.

Hence, the authors encourage widespread adoption of the American Academy of Pediatrics' policy statement about patient- and family-centered care: "In pediatrics, patient- and family-centered care is based on the understanding that the family is the child's primary source of strength and support. Further, this approach to care

recognizes that the perspectives and information provided by families, children, and young adults are essential components of high-quality clinical decision-making, and that patients and family are integral partners with the health-care team” (2, pp, 394–404).

There was also an observed absence of empathy at certain points throughout this patient experience: the nurses who rushed the patient out of her room in the middle of the night, the pediatrician who wouldn’t admit this case was beyond his expertise, and an ED physician who incorrectly diagnosed only according to the data without initially considering the voice and experience of the patient’s mother. “Empathy is challenged by many factors beleaguering healthcare today. We are at a time in medical history when physicians are facing more training requirements and compliance metrics than ever before, ranging from incentives for hand washing to required communication skills training to improve patient satisfaction. In addition, physicians are facing tremendous pressures in terms of the number of patients they are expected to see, the short amount of time in which they have to see them, the complexity of the health problems, and increasingly burdensome documentation requirements” (3). Although this statement is referencing physicians, health-care is an interprofessional environment and more effort should be made by all practitioners and caregivers to exhibit empathy despite a demanding work environment.

Furthermore, for each one of the described health-care interactions, due to their urgency and time of day in which they occurred, the patient’s mother was dressed down and did not “look” like a health-care administrator or professor. There were assumptions made by the providers delivering care that the mother was a single parent since she had arrived with her daughter alone (while her husband was home with their 2 sons). A Harvard sweatshirt changed the dynamic of the conversation so that the respect level in the examination room was elevated. “The social determinants of health are the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels” (4). Considering the social determinants of health as they pertain to each and every patient encounter can contribute to tailoring the pathway to recovery, while delivering care that is both empathically and scientifically sound. Information on this front can be acquired from the patient and their family by asking questions and listening to their responses.

Conclusion

This case highlights areas in need of improvement between the patient/parent–clinician relationship so that the goal of efficiently coproducing health care can be achieved. In 3 instances, the correct diagnosis was made possible due to the active advocacy of the parent of the

patient (eg, acute appendicitis, postsurgical bladder adhesions, and Epstein-Barr virus). A lack of empathy was demonstrated in several instances (eg, late night move by nurses focused on a single task, a pediatrician not willing to admit the case was beyond his expertise, and an ED physician only willing to listen to the data and not the patient’s parent). At 1 point, an observed shift in the patient/parent–clinician relationship was noted based on a social label that was important to the clinician. The authors encourage health-care providers to (a) listen and hear the parents of patients and the patients themselves; (b) practice the art and skill of empathy as the health-care setting can be overwhelming for patients and their parents, and (c) consider the impact of the social determinants of health on one’s health status to date, making sure that any barriers to care are addressed.

Not every parent, patient, or caregiver is comfortable questioning authority or knows enough about the health-care system to ask the right questions. What about the parent who would follow the initial advice of a surgeon to bring their child home regardless of the fact that parental intuition told them otherwise? The health-care system needs to better empower patients and their families to be active participants in overall care so that patients, parents, and clinicians are working together to coproduce health. Listening to the patient and family, exhibiting empathy, and understanding the social determinants of health that may affect the coproduction of health are important factors when working to assure the public health and health-care missions. Not only are these skills taught in health professions’ education, they’re often the driving factors behind the motivations of those contributing within the health-care arena. As our patients continue to present perplexing signs and symptoms, we must strive to strengthen our commitment to not only practice what we are taught in health professions’ education, but that we consciously make an effort to include patients and their families in the coproduction of their health care.

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