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2019

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## Co-producing healthcare in a volume vs. value-based healthcare system: perspective of a parent of a patient and a health professions' educator

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### Abstract

The Institute for Healthcare Improvement's Triple Aim framework represents an approach to optimizing a health system's performance by focusing on improving the patient experience of care, improving the health of populations, and reducing healthcare costs. As the US healthcare system undergoes substantial reformation and a shift from fee-for-service payment to value-based models, an approach that emphasizes the co-production of healthcare, our healthcare system must work in concert with the Triple Aim to improve the health experience for patients across multiple environments. Co-production in healthcare means that patients contribute to the provision of health services as partners of professional providers. To highlight how the current healthcare model failed a patient by delaying diagnosis and subsequent care, thus causing undue suffering, the personal experience of one of the author's children is reported as a narrative. The purpose of communicating this patient experience is to: 1) remind healthcare providers about the importance of not only listening, but hearing the patient and their parent's concerns; 2) readily admit when a patient's clinical presentation falls outside of their expertise; and 3) co-produce healthcare by working with the patient and their family. This patient experience serves to reinforce the commitment to co-produce health with patients and their families in a manner that emphasizes the value of care.

### Keywords

Patient experience, missed diagnosis, co-producing healthcare, value-based care, advocacy

### Introduction

The Institute for Healthcare Improvement's Triple Aim framework represents an approach to optimizing a health system's performance by focusing on three areas: "improving the patient experience of care (including quality and satisfaction), improving the health of populations, and reducing the per capita cost of healthcare"<sup>1</sup>. As the US healthcare system undergoes substantial reformation and a shift from fee-for-service payment to value-based models, an approach that emphasizes the co-production of healthcare, our healthcare system must work in concert with the Triple Aim to improve the health experience for patients across multiple environments. Co-production in healthcare means that patients contribute to the provision of health services as partners of professional providers. This can take place between: government and patient organizations; the healthcare institution's board of directors and their client council; and healthcare professionals and patients.<sup>2</sup> Co-producing health, similar to a population health management approach, involves changes in the organization, management, and delivery of healthcare services so they become more clinically effective, more cost-effective, and safer<sup>3</sup>.

To highlight how the current healthcare model failed a patient by delaying diagnosis and subsequent care thus

causing undue suffering, the personal experience of one of the author's children is reported as a narrative. The purpose of communicating this patient experience is to: 1) remind healthcare providers about the importance of not only listening, but hearing the patient and their parent's concerns; 2) readily admit when a patient's clinical presentation falls outside of their expertise; and 3) co-produce healthcare by working with the patient and their family. This patient experience serves to reinforce the commitment to co-produce health with patients and their families in a manner that emphasizes the value of care.

### Patient Experience

#### *Complex Case*

The first part of my daughter's health journey began on April 26, 2017 when she suffered a ruptured appendix that was misdiagnosed as a ruptured ovarian cyst. She suffered for more than 24 hours before an MRI visualized the source of her pain. She underwent an appendectomy and due to adhesions that subsequently formed around her bladder as a result of the appendectomy, she underwent two more abdominal surgeries in Fall 2017 and Spring 2018. While recovering from her initial bladder adhesion surgery, my daughter contracted the Epstein-Barr virus and experienced a subsequent relapse in Spring 2018. To manage the resultant mononucleosis, her treatment

regimen, as recommended by pediatricians and an ear, nose, and throat specialist involved doing nothing at all, taking a steroid, and following a treatment program for allergies when my daughter had never been diagnosed with allergies. Interwoven in this abridged account were experiences of a lack of empathy as demonstrated by a late night hospital room move by nurses more focused on their assigned task than the patient; a pediatrician not willing to admit the case was beyond his expertise when my daughter presented with unexplained abdominal and back pain; and an ED physician only willing to listen to the laboratory results and not the patient's parent.

My daughter's journey continued when she woke on September 4, 2018 with severe back pain that was characteristic of sciatica. She had experienced sciatic-like pain on three prior occasions following her appendectomy and subsequent adhesion surgeries but there were many competing health issues during these times that treating the sciatica with a non-steroidal anti-inflammatory medication and alternating heat and ice applications seemed to eventually resolve the situation. However, this episode occurred six months following the last abdominal surgery and ranked a nine out of ten on the pain scale. I brought my daughter to the pediatrician who examined her and ordered an X-ray which illustrated a decreased space between the spinal lumbar vertebrae four and five. She was referred to an orthopedic surgeon who ordered an MRI that illustrated a normal, healthy spine despite my daughter having visited the emergency room to help manage the pain with medication and she was now only able to walk with crutches. My daughter was referred to physical therapy with no explanation from the pediatrician or orthopedic surgeon how an adolescent wakes one morning with unexplained severe back pain and no history of trauma to the area.

On October 13, 2018, my daughter woke with severe right foot pain. At this time, she was receiving physical therapy for her back which was helping to ease her pain. The foot pain ranked a nine out of ten on the pain scale and the foot became swollen and appeared bruised despite no history of trauma to the area. I took her to a podiatrist who ordered an X-ray which showed a normal foot. To rule out a tarsal coalition, an MRI was ordered which indicated swelling in the tissues but an otherwise healthy foot. My daughter's right foot was placed in an air cast boot to help provide support and to assist her with walking. We were referred to another podiatrist in the practice who recommended we seek care at the only tertiary care facility in New Hampshire to which I was told there was no pediatric neurologist available there to see my daughter.

### ***Specialty Care***

While my daughter was experiencing these unexplained pain episodes, I conveyed my worry and frustration to her

pEDIATRICIAN about seeing so many specialists and always communicating the abridged version of her health journey to provide context for the visit; only to leave with no answers and more questions. At this point, I requested assistance for my daughter to be seen by specialists at a nationally recognized children's hospital.

My daughter was accepted into the Pediatric Diagnostic Program at the nationally recognized children's hospital. Medical records from the originating episode of a ruptured appendix on April 26, 2017 to the present day were reviewed prior to our visit, at which it was required that parents accompany the child during the examination and be interviewed about the living environment and how we, as a family, helped to manage her pain. My daughter was seen by a psychologist, neurologist, and nurse at the nationally recognized children's hospital Pediatric Headache Program where her medical history was reviewed; we completed a series of validated survey instruments about her attitudes and our practices pertaining to pain management and daily functioning; a physical examination of my daughter was conducted; and an hour and a half meeting with the team discussing my daughter's case with her, my husband, and I. The outcome of this appointment was a diagnosis of post-inflammatory and post-infectious small fiber neuropathy pain, as well as new daily persistent headache resultant from the appendectomy that occurred in April 2017. A subsequent visit to the Pediatric Diagnostic Program at the nationally recognized children's hospital included a meeting with a psychiatrist, rheumatologist, and pediatrician and director of the Pediatric Diagnostic Program. These meetings followed a similar protocol where a review of my daughter's medical records was conducted prior to our visit, we completed validated survey tools, my daughter underwent a physical examination and provided blood for laboratory testing, and we met with each specialist for a 1.5-2.0 hour meeting, as a family, over the course of two days. This group of specialists concurred that my daughter is suffering from a pain amplification syndrome that resulted from the appendectomy which her body viewed as a trauma.

My daughter's treatment plan reflects the multidisciplinary approach of review and care practiced at this specialty hospital. She has been prescribed to engage in regular physical therapy as a medical intervention for her head and neck due to daily headaches and her foot due to the continued swelling and pain. She has also been prescribed a daily low dose of a nerve pain medication to help ease her discomfort. With respect to lifestyle modifications, she now participates in aqua therapy to increase her aerobic exercise level as she has not been able to participate in school sports since the ruptured appendix and her body has become deconditioned. In addition, she has a sleep hygiene remedy to follow which is directed at her being able to sleep uninterrupted for 8-10 hours per

night; she practices meditation and deep breathing exercises to help manage the pain and accompanying stress; and she needs to maintain a regular, well-balanced diet and drink plenty of water to stay hydrated. She has begun to participate in cognitive behavioral therapy to learn and practice pain and stress management techniques; and we have initiated an academic accommodation with her school to allow for a quiet space for her to take exams; drink and eat in class, if necessary; and allow additional time to complete assignments due to her chronic fatigue and pain.

### ***Missed Diagnosis***

The timeframe for when my daughter's pain issues began and when we were seen several times a week, and sometimes daily, by healthcare practitioners, until her diagnosis by the nationally recognized children's hospital's Pediatric Diagnostic Program involved a span of three months. For three months, my daughter suffered, and we were told by healthcare providers in our area that the diagnostic tests indicated a normal back and foot. Despite seeing my child in severe pain and presumably listening to my communication of her medical history to provide context as to why we were in the office for an appointment, at no point did any physician state they did not know what was wrong with her; that the diagnostic testing results did not coincide with the physical manifestation of signs and symptoms presented to them; or help to find a resource that might offer assistance. We were seen in the office for the requisite 15-minute appointment, albeit some were longer and may have lasted 45-60 minutes while we waited on test results, but we always left with no further information or direction for care.

“Current estimates suggest that as many as one of every four children today will experience an episode of pain lasting three months or longer before reaching adulthood. Of those who experience chronic pain, 77 percent will have more than one kind of pain problem. Moreover, the overall incidence of pediatric pain conditions is on the rise; over the past twenty years, reports of chronic headache and abdominal pain syndromes have almost doubled”<sup>4</sup>. Furthermore, “chronic pain is one of the most common problems in pediatrics, with approximately 1.7 million children currently suffering from moderate to severe chronic pain. It is also one of the most expensive pediatric problems, costing 19.5 billion dollars per year...”<sup>4</sup>. Pain-related experiences may arise from pediatric disease (e.g., juvenile rheumatoid arthritis, irritable bowel disease, cancer) and non-disease-related situations (e.g. post-surgical pain, migraine)<sup>4</sup>. These estimates suggest pain as a pediatric health issue is widespread, yet, the healthcare providers (many of whom were pediatric specialists) who evaluated my daughter, prior to the specialists in the Pediatric Diagnostic Program, did not mention a chronic pain condition due to her appendectomy.

### **Reflection and Recommendations**

As a health professions' educator who studies and teaches how to manage the health of populations, I have reflected on my daughter's health journey from a fee-for-service standpoint where the costs for her care for just the pain experienced since Spring 2018 were \$20,000 (sans the nationally recognized children's hospital Pediatric Diagnostic Program billed charges when a diagnosis was finally determined). Those healthcare costs were paid by our health insurance provider and as out-of-pocket expenses. That is a significant amount of money to spend and not receive a diagnosis and treatment plan and/or an offer of assistance to work with us to help find a resource that could potentially help alleviate my daughter's suffering considering how prevalent her condition is among a pediatric population. In a value-based system of care, “providers are rewarded for helping patients improve their health, reduce the effects and incidence of chronic disease, and live healthier lives in an evidence-based way”<sup>5</sup>. In our fee-for-service model, co-producing healthcare with my daughter's physicians is not a priority and the system works as it was designed, that is, the providers were reimbursed for the volume of healthcare services delivered and not actually improving health, as would be prioritized in a value-based system of care.

Until we have implemented a value-based healthcare system, I recommend the 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 healthcare team”<sup>6</sup>. This statement of practice is endorsed by a premier professional association and should be consistently implemented as a best practice when co-producing healthcare for a pediatric patient.

A significant barrier to care in a fee-for-service practice environment is the volume incentive and not a quality of care incentive. There is no incentive for a physician to admit when a patient's clinical presentation falls outside of their expertise. As a health professions' educator, I was seeking care for my daughter with the presumption that I was working with healthcare providers who are knowledgeable and transparent in their care giving. By not admitting that my daughter's clinical presentation was beyond their expertise, the healthcare providers from whom we sought care, prolonged her suffering, decreased the quality of care delivered, and increased the cost of care; a practice in opposition of the Triple Aim.

“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 co-production of their healthcare”<sup>7</sup>. This sentiment must prevail regardless of the fee-for-service practice environment which limits this integral relationship among patient, family, and provider. If the co-production of healthcare was a priority for the healthcare providers seen prior to the providers seen at the nationally recognized children’s hospital Pediatric Diagnostic Program, then unnecessary suffering could have been avoided. I do not believe the healthcare providers who examined my daughter were “heartless.” I believe our volume-based system has created a “perfect storm” that allows for a missed diagnosis to be acceptable and reimbursable. We are fortunate in that our daughter benefitted from a multi-disciplinary care team that quickly identified a “common” pediatric issue and developed a treatment plan from which she has already experienced progressive relief. Further, based on our experience, I often reflect on the parent who may not know the questions to ask, the resources to access, and who are unable to allocate the requisite time and finances necessary to co-produce healthcare for a loved one in a fee-for-service environment.

Areas in need of improvement while providing care in our current healthcare environment include the patient/parent-clinician relationship so that the goal of efficiently and effectively co-producing healthcare for complex, yet not rare, pediatric cases can be achieved. By not admitting that my daughter’s clinical presentation was beyond their expertise, the healthcare providers from whom we sought care, prolonged her suffering, decreased the quality of care delivered, and increased the cost of care. If the co-production of healthcare was a priority for the healthcare providers seen prior to the providers seen at the specialty hospital, one can speculate that there may have been no need to visit a multi-disciplinary facility. Therefore, healthcare providers are encouraged to 1) practice not only listening but hearing the patient and their parent’s concerns; 2) readily admit when a patient’s clinical presentation falls outside of their expertise; and 3) co-produce healthcare by working with the patient and their family.

This case represents several sensitive issues including physician inexperience; the lack of time to adequately address a patient’s suffering in the current healthcare environment; missing a common, complex pediatric diagnosis; and, the absence of co-producing healthcare with a patient and her family. These are issues worth

discussing so that we can learn how to deliver quality healthcare in a fee-for-service environment and an eventual value-based care system.

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