Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach Throughout the Lifespan 16 (2023) 443–447
DOI:10.3233/PRM-230027
IOS Press

Case Report

Medicine shouldn't be this hard: The intersection of physician moral injury and patient healthcare experience in pediatric complex care

Erika Erlandson[a,*], Carrie Ramirez[b] and Wendy Dean[c]
[a]*Departments of Pediatrics and Physical Medicine and Rehabilitation, Michigan State University College of Osteopathic Medicine, Lansing, MI, USA*
[b]*General Motors Incorporated, Lansing, MI, USA*
[c]*Moral Injury of Healthcare, Carlisle, PA, USA*

Received 30 May 2023
Accepted 7 August 2023

Abstract. Dr. Jay Neufeld's story in *If I Betray These Words* is a detailed account of one physician's catastrophic journey through moral injury when caring for pediatric patients with complex medical conditions [1]. Many clinicians may recognize Jay's journey in their own experiences, but what deserves parallel consideration are the journeys of patients and families when they are accompanied by physicians at risk of moral injury. This case study illustrates the tight link between drivers of physician moral injury and patients' negative healthcare experiences. These include (1) decisions directed by health insurance regulations and prior authorizations; (2) the electronic medical record (EMR); and (3) healthcare systems focused on revenue generation.

Keywords: Moral injury, physician, patient experience, electronic medical record, prior authorization

1. Dani's story

Prior to January of 2022, Dani led a "normal" life, working hard in seventh grade, doing art in their free time, and looking forward to a career with animals. Then their illness started. Hip, knee, and ankle pain with fatigue came first, progressing quickly to muscle spasms, stiffness, and loss of hand dexterity. Evaluated by General Pediatrics, Pediatric Rheumatology, and Physical Therapy, Dani was diagnosed with post-viral syndrome, specifically Long COVID. On the first visit to the Pediatric Rehabilitation Medicine Clinic, Dani said, "My hands are broken." Their fingers could not extend, limiting functional independence. On physical exam, both hands were flexed at the distal interphalangeal (DIP) and proximal interphalangeal (PIP) joints, with clonus during passive range of motion. Deep tendon reflexes were 3+ in upper and lower extremities. The physiatrist was worried about the upper motor neuron findings and decided to order an MRI and consult Pediatric Neurology.

---

*Corresponding author: Erika Erlandson, MD, Associate Professor, Department of Pediatrics and Physical Medicine and Rehabilitation, Michigan State University, College of Osteopathic Medicine, 1200 E. Michigan Ave, Suite 520, Lansing, MI 48912, USA. Tel.: +1 5173645260; Fax: +1 5173645406; E-mail: erlands6@msu.edu.

2. Insurance woes

Unfortunately, while awaiting insurance prior authorization and access to the specialists to establish a diagnosis, Dani's symptoms progressed, necessitating Emergency Department evaluation and hospital admission, a shockingly common occurrence. According to a 2022 American Medical Association survey, 46% of physicians reported that prior authorization policies led to urgent or emergency care for their patients [2]. Dani's ultimate diagnosis was Stiff Person Syndrome (SPS), an autoimmune disorder that targets the nervous system and leads to unopposed muscle contraction.

Two hospitalizations were required for diagnostic work up and another for implantation of an intrathecal baclofen pump. After Dani's third hospital stay, Dani and their neurologist chose to proceed with subcutaneous immunoglobulin (SCIG) for definitive treatment because it is equally as effective as intravenous immunoglobulin (IVIG) but does not require a central line for infusion and significantly decreases the risk of infection. In addition, SCIG is more amenable to pediatric patient lifestyles, with more flexibility in infusion times and intervals. But, in this case, the health insurer denied payment and recommended IVIG instead. Contravening medical evidence, the insurer cited "increased risk" of SCIG as the reason for denial.

On news of the denial, the neurologist immediately ordered IVIG with dosing every three weeks; it was suboptimal but better than going without immunoglobulin or the family paying $14,502 out of pocket for each treatment. Unfortunately, IVIG treatment also needed approval. For weeks, the physician's office and the family repeatedly called the insurer, urging approval, but the insurer made no determination. Finally, Dani was hospitalized for "emergent" IVIG due to significant escalation of their SPS symptoms from delayed treatment.

Physicians are at risk for moral injury ("... simultaneously knowing what care patients need but being unable to provide it due to constraints that are beyond our control" [1]) when insurance companies steer medical decisions by restricting payment, effectively taking decisions about the course of diagnosis and treatment out of physicians' hands. Prior authorization is necessary to spare patients financial toxicity, but authorization delays meant higher acuity care for Dani and potentially worse long-term outcomes, all of which were easily preventable with prompt treatment. Physicians regularly see such crises approaching as delays mount, knowing what will result, yet are powerless to stop them. How can physicians practice patient-centered medicine in a business model that allows payers to negate doctors' decision-making authority and delay medically necessary treatment?

Dani spent a total of 29 days as an inpatient in 2022, most of which were avoidable. What was this like for 13-year-old Dani, who just wanted to get back to "normal?" What about the parents, who initially watched an unchecked illness rob their child's function, while insurance dithered, and then watched avoidable hospitalizations eat away at Dani's resolve? All three were frightened during the initial emergency room visit and hospital stay, fearing there might not be an answer, or it might come too late. Once they had a diagnosis, and given its seriousness, they thought navigating care would be easier. Surely, their insurer would act quickly and follow their doctors' recommendations. But, the frustrations and delays persisted. Dani understood monitoring was necessary for the loading dose of IVIG and reluctantly agreed to the fourth hospitalization. But a fifth hospitalization, for maintenance treatment that could have been given at home, felt unbearable. Dani was on the verge of giving up hope and Dani's mom, Cindy, a tireless advocate, was desperate for relief for her child.

That fifth hospitalization coincided with the first week of eighth grade. Cindy described her heartbreak, "In a matter of seconds, Dani went from stunned to tears of frustration and disappointment. We had hoped that eighth grade would be 'back to normal.' Instead, we were back to the hospital and the pain was still present all day, every day. Dani was missing everything that goes with the start of a new year: reuniting with friends, connecting with new teachers, practicing with the marching band, and even school pictures."

Cindy had been relentless with the insurance company, checking and recording the status of approvals daily. She contacted the pharmacy, home infusion company, and physician clinic at least three times weekly for status updates. She spent at least five hours *each week* on such tasks and, in the worst weeks, eight or more. Cindy tried to advocate, but the machinery of medicine was immovable. She pivoted to supporting Dani through another unnecessarily disruptive hospitalization. The decisions of the health insurance company not only caused moral injury for the physician, but emotional harm to the patient and their family.

3. The EMR

The EMR is another source of moral injury for physicians and patients alike. The HITECH Act of 2009 promoted the adoption and use of health information technology in the United States with the following goals: improve quality, safety, and efficiency; engage patients in their care; increase coordination of care; improve the health status of the population; and ensure privacy and security [3, 4]. While well-intended, the EMR has not lived up to its lofty promises, particularly in the realms of efficiency and coordination of care.

Most EMRs are proprietary to their health systems and purposefully do not communicate with other health systems' EMRs. Information cannot transfer across platforms, so rather than instantaneous digital access, intersystem care coordination still too often relies on faxing, scanning, and uploading outside information, relics of the days of paper charts prone to errors, omissions, and delays. The cumbersome process has real implications for patients: delays in treatment, lost referrals, and lagging test results or clinician communications. Direct physician-to-physician communication may seem like a simple solution to this problem, but, as reported by Dean and Talbot, "The simultaneous pressures of formalized communication in the EMR and productivity metrics have led clinicians to work in isolation... the camaraderie between various specialties, even across health systems, has contracted" [1].

Dani's local hospital did not have all the expertise to manage their illness, requiring referral to academic centers in larger cities. Dani saw doctors in six different healthcare systems that had six different electronic medical records, none of them interconnected. For all parties involved, patient, family, and physician, the EMR was a burden rather than a blessing.

Cindy and Dani used the patient portal feature of four of the six EMRs, and each system used a different application. Every electronic appointment check-in was a 15-minute ordeal that required confirmation of patient information, insurance, medications, and allergies, but because the systems were not interconnected, updates in one system did not populate to the others; each needed to be updated separately. In addition, nonstandard medications, like Dani's intrathecal baclofen, were not found in drop-down menus, meaning that some of the most vital information had to be manually entered and, consequently, was even more prone to error.

Cindy carried the burden of coordinating Dani's care across systems. "Dani's health portals are touted as a lifeline," she said. "Dani's situation is so complicated; I exchange messages with physicians multiple times a month. I review notes, see lab results, and make sure I understand the plan. However, this access comes with a big price, especially since none of the portals talk to each other." She continued, "I have to review and ensure information flows from one system to another so each specialist has access to the latest information. By choice, I only maintain the four most important portals because managing them takes a lot of time, energy, and entails serious frustration. The med lists are never right and notes from specialists rarely get transferred from one system to the other without at least one prompt. In addition, our access to the most important portal is shut off regularly because of Dani's age. Well-meaning administrators, trying to follow policy and protect Dani's right to privacy, have shut off access eight times to date. As luck would have it, the access usually gets shut off when Dani is struggling and we need it most."

Dani found EMRs exhausting. Even though Cindy completed the electronic check-ins, each visit began with a 20-minute process of confirming the same information. Dani's stamina was limited and these interactions drained energy but added no value to care. Dani was worn out before the physician even entered the room. This compromised communication with the physician, eroded patient autonomy, and ultimately risked degrading the care offered. Cindy said, "When Dani is feeling the worst, the routine is exhausting and, to be honest, overwhelming. Dani's entire health journey is re-lived through every visit because, inevitably, there are mistakes in the EMR. On the advice of Dani's counselor, we created a system to navigate communication in these instances whereby Dani gives me a signal and I take over. This allows Dani to save as much energy as possible for the actual exam and to be part of determining next steps."

As one of Dani's primary providers, author EE's experience mirrored both Cindy's and Dani's. She watched Dani wilt while reviewing their history, confirming record accuracy, and updating information from other sub-specialty visits. To provide Dani the best possible care, EE had to facilitate coordination and communication between physicians. However, this process was time consuming and frustrating. The outpatient clinic was located across the street from the local hospital, but the clinic and hospital used separate medical records. This meant EE must access two EMRs to obtain information from the hospital, including her own notes. Once accessed, the two systems could not be more different in interface, and neither was intuitive. Finding information from outside health systems was clumsy and could take days or weeks, which often interfered with decision-making during appointments. Ultimately, Dani's care was less efficient. EE had to dig through the record, delay decisions while awaiting information that *should* be available were EMRs working as promised, and follow up later with Dani to confirm a final plan of care. The EMR, according to policymakers at the time of the HITECH Act, was supposed to deliver "the right information to the right people at the right time" [5]. Nearly fifteen years later, EE and Dani were still waiting.

4. Revenue

The discussion of moral injury cannot exclude healthcare systems' focus on the bottom line. Unfortunately for Dani, this was also part of their journey.

During the wait for IVIG treatment, Dani's condition significantly deteriorated. The pediatric neurology team deemed plasmapheresis, in addition to IVIG, medically necessary. Plasmapheresis filters harmful antibodies from the blood of patients with autoimmune disorders and, in Dani's case, treatments would be needed every other day for 10 days. Although Dani had received other treatment at the local hospital, plasmapheresis was not available for pediatric patients because reimbursement did not cover the cost of providing the service and put the hospital at financial risk. The alternative was to admit Dani to a hospital 60 miles from their home.

The ordering neurologist recognized the hardship for Dani's family and challenged the hospital's decision, since they provided the exact same service to adult patients. She demanded an emergency contract addendum for Dani's treatment arguing that, in pediatrics, the entire family must be considered in the care plan and extended treatment far from home was not in the patient's best interest. Though treatment was again delayed during negotiations, the neurologist prevailed. The hospital later published this experience as a "success" story of exceptional patient care offered by the neurologist and their healthcare system. But the success started with a physician who refused to acquiesce to an expectation of providing care in the best interest of the health system, rather than in the patient's best interest.

Cindy described the upheaval of contemplating treatment at a distant medical center. Simple things, like packing comfort items and entertainment for Dani, were suddenly more complex when they would be far from home and unable to drop in for forgotten items. Cindy described the impact on Dani, "Dani was now much more stressed about the plan. Initially, it was fear around the placement of the central line and the new experience of plasmapheresis. Now, Dani was worried about learning a new hospital and its staff, separation from their dad and siblings, and preparing for the time away. It felt much heavier than it did when we were close to home."

Cindy also shared her empathy around the time invested by the neurologist to provide Dani and the family with the best possible care. Cindy said, "I know our neurologists have supported and fought for us, probably at the expense of themselves and their families. I also know, from my own career, that escalating service issues through management, initiating legal engagement, writing addendums, and negotiating contracts takes a significant amount of time and energy. I expected a long delay and was surprised when the changes were made in only a couple of days. For things to move so quickly, I knew they must have spent hours working to help us. The gratitude we felt for the effort was immense, but I also felt bad that it might have taken so much from others." This is a clear example of how revenue-generating decisions have a direct impact on the practicing physician and care received by the patient.

Dani's story complements those of Dr. Jay Neufeld and other physicians in *If I Betray These Words* by adding the health journey of patients and their families. Health insurance policy should not interfere with physician decision-making, and necessary medical treatment must be available to patients without significant barriers. Reducing the EMR burden on both physician and patient must start with true system interconnectivity and follow with more intuitive user interfaces. Removal of extraneous data (populated for billing purposes) from physician notes would improve care coordination by highlighting important medical decision-making, treatment recommendations, and vital information for patient care. And finally, health systems must recommit to aligning their values with the patient, rather than profit, as their priority.

Clinicians and patients alike know and live these challenges every day. A forefront goal in the care offered by a Pediatric Rehabilitation Medicine physician remains to optimize function and quality of life.

Biopsychosocial factors play key roles in quality of life in children with chronic illness and disabilities. When health system policies interfere with improving children's quality of life, it contributes to the moral injury of their physicians. Change must be advocated for through every channel available: work together to raise awareness, influence hospital administration, bravely share personal stories with state and federal representatives to educate them about necessary changes to legislation and insurance reform, and demand technology improvements from the health systems. Lives may depend on it.

Acknowledgments

Dr. Suad Khalil, Dr. Kabelo Thusang.

Conflict of interest

The authors have no conflicts of interest or funding to report.

Ethical considerations

This blinded case study is exempt from IRB approval. Written informed consent was obtained from patient and guardian. Real names have not been used.

References

[1] Dean W, Talbot S. If I Betray These Words. Lebanon, NH, Steerforth Press; 2023.

[2] American Medical Association [homepage on the Internet]. Chicago, IL: American Medical Association; 2023 [updated 2023 Mar 29; cited 2023 Aug 11]. Available from: https://www.ama-assn.org/

[3] US Department of Health And Human Services [homepage on the Internet]. Washington DC: US Department of Health And Human Services; 2009 [updated 2009 Feb 19; cited 2023 Aug 11]. Available from: https://www.hhs.gov/

[4] The HIPAA Journal [homepage on the Internet]. Sherman Oaks, CA: HIPAA Journal; 2023 [updated 2023 May 9; cited 2023 Aug 11]. Available from: https://www.hipaajournal.com/

[5] Commonwealth Fund Newsletter. New York, NY: The Commonwealth Fund; 2011 [updated 2011 May 1; cited 2023 Aug 11]. Available from: https://www.commonwealthfund.org