

Diagnostic Uncertainty and Ethical Dilemmas in Medically Complex Pediatric Patients and Psychiatric Boarders

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Pediatric hospitalists face many patients with diagnostic and therapeutic uncertainty. Confronted with this issue, they may question their obligation to continue treatment plans they do not agree with or are not comfortable providing. Additionally, hospitalists manage an increasing number of patients with psychiatric disease, as the lack of intensive psychiatric services has placed a greater burden of behavioral problems on inpatient care wards. We offer the following case to consider the ethical obligations of the hospitalist to continue an outside provider's treatment plan and how to provide the best care of complicated psychiatric patients without a disposition.

CASE PRESENTATION

An adolescent young man presents to the emergency department after ingestion of a nontoxic household product. He is admitted to the hospitalist service due to continued decline of executive functions, increased self-neglect, and increase in bizarre behaviors. His past medical history is significant for receptor-negative autoimmune encephalitis diagnosed 2 years before presentation.

By report, he was a healthy, normally developing child until 2 years ago when he began having bizarre movements, repetitive behaviors, emotional lability, intrusive thoughts with hallucinations and hearing voices, and progressive cognitive decline. A diagnosis of receptor-negative autoimmune encephalitis was given at an outside institution, as extensive laboratory work and imaging were negative for a specific diagnosis. The patient was treated with intravenous infusions of immunoglobulin (IVIG), steroids, and additional immunomodulators, administered in the PICU for behavioral concerns, with little improvement. Psychiatric diagnoses, including schizophrenia, were considered previously but not seriously regarded by the family. His interim behavior after treatment has been difficult to control, including running away requiring an Amber alert, aggression toward family members, and severe neglect of self-care. There is no history of overt suicidal thoughts or behaviors. No focal neurologic findings were present to suggest intracranial pathology. Attempts to engage the patient in conversation were met with intermittent 1-word answers without eye contact.

Now admitted to a new institution, his lengthy hospitalization was complicated by multiple patient and care provider issues. Patient issues included refusal of self-care, attempts to steal other patients' food and ingest nonfood items, and sexualized behaviors that were difficult to redirect. Hospital security was required on multiple occasions for elopement to other patient care units and public areas. Care delivery issues included diagnostic and therapeutic uncertainty among providers, reluctance to consider psychiatric disorders among the family, professional and

www.hospitalpediatrics.org

DOI:10.1542/hpeds.2016-0032

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HOSPITAL PEDIATRICS (ISSN Numbers: Print, 2154-1663; Online, 2154-1671).

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

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ethical obligations with care directed by multiple providers (some of whom were not practitioners at the admitting hospital), and difficulty in finding appropriate discharge placement due to parental refusal for home discharge or inpatient psychiatry placement. Exploration of care delivery issues are detailed as follows.

DIAGNOSTIC UNCERTAINTY: THE PATIENT HAS AUTOIMMUNE ENCEPHALITIS...BUT WHAT IF HE DOESN'T?

Encephalitis refers to an inflammatory disorder of the brain resulting in altered mental status, seizures, or focal neurologic deficits, usually accompanied by signs of inflammation in the cerebrospinal fluid and MRI findings ranging from normal to extensive abnormalities.¹ The causes of encephalitis are numerous, and extensive investigations for infectious agents and other etiologies are often negative.¹ Moreover, the broad spectrum of symptoms, including psychosis, catatonia, alterations of behavior, abnormal movements, and autonomic dysregulation, make a definitive diagnosis difficult without immunologic markers.¹

Autoimmune forms of encephalitis have been associated with autoantibodies against synaptic cell-surface antigens, such as N-methyl-D-aspartate- and α -amino-3-hydroxy-5-methyl-4-isoxazolepropionic acid-type glutamate receptors, γ -aminobutyric acid B receptor, and leucine-rich glioma inactivated 1.¹ Although our patient had a negative workup to date, it remains unclear how many synaptic autoantigens are yet to be defined.¹ In our case, a diagnosis of autoimmune encephalitis was made at an outside institution based on behavioral consideration without conclusive laboratory and imaging data to support this diagnosis. Despite belief in the diagnosis, the family was unhappy with the rest of the care at that institution and pursued medical treatments elsewhere. The care team raised the concern that seeking a new institution could imply neglect by abandoning previous therapeutic options they disagreed with or Munchausen by proxy, in which the family was doctor shopping to find someone to

support their thoughts. After further record review and discussions with the family, child protection consult was deferred, as there appeared initial support for the diagnosis and compliance with previous treatment plans for autoimmune encephalitis. A significant consideration in this patient's case was fixation of the family on previously proffered diagnosis and unwillingness to expand diagnostic evaluation.

A major consideration for his hospitalist providers was schizophrenia.² In agreement with the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* criteria for schizophrenia, the patient exhibited disorganized speech, grossly disorganized and catatonic behavior, negative symptoms coupled with social dysfunction for at least 6 months, and failure to achieve expected levels of interpersonal and academic achievement. His symptoms were not related to substance abuse or other metabolic derangement, with multiple negative toxicology screens, normal electrolytes, and a normal lead level. Attempts to discuss this diagnosis with the family were met with resistance and rejection. The parents would point to the out-of-state national expert who had provided the original diagnosis and treatment plan as the only valid diagnosis, yet the provider team struggled with their own certainty in this regard. Is the team obligated to the diagnosis of another expert? In our case, there was enough concern for an alternative diagnosis that a concrete treatment plan and limited length of treatment were established with the family, discussed as follows, so that the issue could be readdressed.

THERAPEUTIC UNCERTAINTY

The patient initially continued his previous outpatient plan with additional IVIG infusions (requiring transfer to the PICU for intravenous placement and medication administration) with no improvement. After extensive care conferences with hospital providers, including neurology, rheumatology, and his primary out-of-state expert, it was determined a course of cyclophosphamide, rituximab, pulse steroids, and IVIG would be administered for 3 months. However, there was staff division

regarding the treatment plan. One issue discussed was the potential risks given the uncertain diagnosis and lack of improvement with similar treatment over the previous 2 years with the potential of additional harm with this more-aggressive regimen. Cyclophosphamide possesses potent immunosuppressive activity and puts the patient at risk for hemorrhagic cystitis and sterility.³ Rituximab can cause prolonged cytopenias, putting the patient at further risk for serious infection.³ Ultimately, the team determined a short trial of the more intensified regimen could be beneficial and help determine if further inpatient care would be warranted. Given the patient's unpredictable behavior, he required sedation and continuous monitoring during his IVIG, cyclophosphamide, and rituximab infusions, necessitating multiple transfers to the PICU. The patient's ongoing behavior and sedation for therapy, although administered only monthly, made disposition challenging. The family did not consent to inpatient psychiatric placement and felt unable to care for him at home. Eventually, a resolution was accepted for transfer to an out-of-state medical psychiatry unit, with retransfers back to the PICU to for his monthly treatment plan. After 3 months, the in-house rheumatologist discussed with the patient's parents that there continued to be no meaningful improvement and further immunosuppressive/immunomodulatory therapies were not indicated, and encouraged other available psychotherapeutic options. The family then decided to pursue care at a different hospital.

PSYCHIATRIC CONSIDERATIONS

Psychiatric disorders account for an increasing number of pediatric hospitalizations. Psychiatric hospitalizations are common and costly nationwide, with nearly 1 in 10 pediatric admissions having a primary diagnosis of a mental health condition.⁴ Children often have to wait long periods of time for placement, as available psychiatric beds have decreased significantly in the United States while psychiatric hospitalization rates have increased.^{5,6} This puts a substantial burden

on pediatric medical inpatient units while delaying psychiatric care. Medical units are ill equipped for providing counseling services, family therapy, and appropriate violence prevention.^{6,7} Patients transferred to an inpatient psychiatric unit are more likely to receive psychiatric medications and counseling than patients boarding on the general pediatric inpatient unit, magnifying the problem.⁷

In our case, our patient was disruptive on the unit, necessitating multiple calls to security as well as requiring a private room and a 1:1 sitter to ensure his safety. It was surmised by the medical team that the stigma of mental health played a significant role, as this often can be a barrier to seeking appropriate care.^{8,9} Parental attitudes, both positive and negative, have been shown to influence the seeking of mental health services.¹⁰⁻¹² Some parents may not use mental health services to avoid their child being “labeled,”¹² which was thought to be a concern in this case. Had there been more appropriate inpatient psychiatric services available on the medical unit, he potentially would have been able to receive psychiatric care sooner, as this would not have carried the stigma of being in a dedicated psychiatric unit. Because of this, psychiatric care was delayed by the family’s reluctance to accept a primary psychiatric diagnosis and refusal of transfer to an inpatient psychiatric unit.

PROFESSIONAL AND ETHICAL CONSIDERATIONS

This case raised a number of ethical issues: autonomy, nonmaleficence, and best interests. Recognition of these issues rarely overtly occurred during the patient’s inpatient stay, as no irresolvable ethical dilemma arose during his care, but in hindsight discussion of these issues may have benefited the team. The patient, although a teenager, did not demonstrate the ability to weigh risks and benefits and was unable to provide informed consent or assent. Parental autonomy regarding decision-making is well recognized, as long as the principle of beneficence or best interests is followed.¹³ Although the parents had the right to participate in decision-making regarding their son’s treatment, at

what point do you respectfully disagree with the parents’ wishes and proceed with a different treatment course when there is concern that their treatment decisions are causing their child more harm than good? Is continuing the treatment plan now harmful and violating the principle of nonmaleficence?¹⁴ One could argue that their treatment decisions were no longer in the best interest of their child because his symptoms failed to improve after multiple powerful immunomodulators were trialed and that their refusal to accept an alternative psychiatric diagnosis was not in the child’s best interest.¹⁴ The hospitalist in this case was concerned, however, that there is enough doubt in a nonspecific diagnosis like receptor-negative encephalitis that treatment still could be seen to have some benefit. Thus, in agreement with the rheumatologist, treatment length was clearly delineated to determine if there was any benefit.

Although medicine is always evolving, when does pursuing diagnostic workup at multiple institutions constitute due diligence, parental thoroughness, and advocacy, and when does it cross the boundary into concern for Munchausen? The American Association of Pediatrics describes Munchausen Syndrome by proxy as, “when a parent or caregiver causes injury to a child by seeking or administering unnecessary and possibly harmful medical treatment for the child.”¹⁵ In our case, the family was reluctant to consider a primary psychiatric disorder, even in the face of failing multiple treatment regimens for autoimmune encephalitis. This was further complicated by family refusal of an inpatient psychiatric placement, prolonging an already long and complicated hospitalization. At what point does parental focus on 1 specific diagnosis and denying consideration of another represent “misrepresenting symptoms,”¹⁵ another sign of Munchausen? In our case, the treatment team ultimately was not concerned for Munchausen by proxy, and felt the family’s actions were out of great concern for their son in conjunction with denial and medical illiteracy.

Recent media attention highlights the conflict between medical providers

questioning difficult-to-make diagnoses without clear criteria and working in the best interest of the child. Justina Pelletier, who was previously diagnosed with a mitochondrial disorder at a different institution, spent 16 months in the custody of the Massachusetts Department of Children and Families, most of it in a psychiatric unit of Boston Children’s Hospital, after physicians felt that although her symptoms may be real, there was no physical root cause after their thorough testing.¹⁶ After significant media coverage and return of the child to the family, care was transferred to Yale-New Haven Medical Center where Justina’s father stated he was pleased that staff at Yale-New Haven focused on physical causes and testing rather than psychiatric issues.¹⁶ This begs the question, which is equally pertinent in our case, just because you find a physician to agree with you, is it necessarily the best course of care? This question plagued our treatment team throughout our patient’s hospitalization and was left unanswered at time of transfer.

CONCLUSIONS

Hospitalists often find themselves caring for patients with diagnostic and therapeutic uncertainty with the assistance of multiple consulting services. Often one “inherits” a diagnosis or treatment plan. Although we want to have the utmost confidence in other physicians and our peers, it is difficult to establish a treatment plan when we disagree. It further compounds the picture when families “shop around” between hospitals and have multiple providers at multiple institutions. There is minimal literature on how to combat “doctor shopping,” and many times is taught to be a possible flag for Munchausen/abuse.¹⁵ Communication among providers, especially when care is across multiple institutions, is critical to avoid families splitting providers and to ensure proper continuity of care. An additional resource should be an ethics consult, which was not used in this case, but allows individuals to discuss their concerns and frame issues.

Diagnostically it can be a challenge when a physician or team takes on a patient who has already undergone an extensive

workup. The family must play a role in ensuring that all records from previous hospitals are given to the treatment team and that they are completely transparent with the data, whether they agree with the findings or not. It can be difficult when families bring forth only the data that support their preferred diagnosis, but it is obligatory that all pertinent care details be obtained.

We must be allies with our patients and their families, working together when there is a difficult diagnostic picture and not pitted against each other. Sharing our doubts and concerns with a diagnosis is critical for the care team so that a dialogue can be constructively started. It may be prudent to have frequent “check-ins” or mini team meetings with key team members to ensure that the patient, the patient’s family, and the medical team are transparent and aligned, as this may decrease tension between the team and the family dealing with small issues as they arise.

In our case, and in many cases involving psychiatric patients, disposition was difficult, necessitating a prolonged hospitalization. Psychiatric patients are becoming an increased burden on inpatient pediatric wards. With little hope of more inpatient pediatric psychiatry beds becoming available, it is pertinent for pediatric inpatient units to work toward providing the necessary care to these patients, including properly trained staff, and therapeutic and psychiatric services.

An often-overlooked part of the team, especially while the child is hospitalized, is the patient’s primary care pediatrician. In our case, the patient’s outpatient pediatrician was not involved by the family in the multiple extensive workups, so the pediatrician could not provide a complete medical record. A key provider organizing such evaluations to work with the family is critical. With an experienced and capable pediatrician, the pediatrician could harbor all the patient’s detailed workups in one place, decreasing the need for repeat

diagnostic tests. With a trusted pediatrician, a family may be more inclined to have their child’s care focused at fewer institutions, as they can trust that their personal physician knows all the intimate details of their diagnostically complex child.

REFERENCES

1. Ohkawa T, Satake S, Yokoi N, et al. Identification and characterization of GABA(A) receptor autoantibodies in autoimmune encephalitis. *J Neurosci*. 2014;34(24):8151–8163
2. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders: DSM 5*. Washington, DC: American Psychiatric Association; 2013
3. Lexicomp Online. Pediatric and Neonatal Lexi-Drugs Online. Hudson, OH: Wolters Kluwer Clinical Drug Information, Inc.; 2015; September 1, 2015.
4. Bardach NS, Coker TR, Zima BT, et al. Common and costly hospitalizations for pediatric mental health disorders. *Pediatrics*. 2014;133(4):602–609
5. Blader JC. Acute inpatient care for psychiatric disorders in the United States, 1996 through 2007. *Arch Gen Psychiatry*. 2011;68(12):1276–1283
6. Fieldston E, Jonas J, Scharko AM. Boarding of pediatric psychiatric patients is a no-fly zone for value. *Hosp Pediatr*. 2014;4(3):133–134
7. Claudius I, Donofrio JJ, Lam CN, Santillanes G. Impact of boarding pediatric psychiatric patients on a medical ward. *Hosp Pediatr*. 2014;4(3): 125–132
8. Bulanda JJ, Bruhn C, Byro-Johnson T, Zentmyer M. Addressing mental health stigma among young adolescents: evaluation of a youth-led approach. *Health Soc Work*. 2014;39(2):73–80
9. Corrigan P. How stigma interferes with mental health care. *Am Psychol*. 2004; 59(7):614–625
10. Dubow E, Lovko K, Kausch D. Demographic difference in adolescents’ health concerns and perceptions of helping agents. *J Clin Child Psychol*. 1990;19(1):44–54
11. McKay MM, Pennington J, Lynn CJ, McCadam K. Understanding urban child mental health I service use: two studies of child, family, and environmental correlates. *J Behav Health Serv Res*. 2001;28(4):475–483
12. Turner EA, Liew J. Children’s adjustment and child mental health service use: the role of parents’ attitudes and personal service use in an upper middle class sample. *Community Ment Health J*. 2010; 46(3):231–240
13. Cummings CL, Mercurio MR. Ethics for the pediatrician: autonomy, beneficence, and rights. *Pediatr Rev*. 2010;31(6): 252–255
14. Diekema DS. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth*. 2004; 25(4):243–264
15. Horsley L. AAP recommendations on Munchausen by Proxy. *Am Fam Physician*. 2008;77(1):97
16. Wen P, Swidey N. A difficult return to hospital for Justina Pelletier. *The Boston Globe*. December 7, 2014. <https://www.bostonglobe.com/metro/2014/12/07/difficult-return-hospital-for-justina-pelletier/u4JXzmt5YsmWhYk95za2aK/story.html>. Accessed September 5, 2015.
17. Hinshaw SP. The stigmatization of mental illness in children and parents: developmental issues, family concerns, and research needs. *J Child Psychol Psychiatry*. 2005;46(7):714–734
18. Hinshaw SP, Cicchetti D. Stigma and mental disorder: conceptions of illness, public attitudes, personal disclosure, and social policy. *Dev Psychopathol*. 2000;12(4): 555–598

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Hospital Pediatrics 2016;6;689

DOI: 10.1542/hpeds.2016-0032 originally published online October 7, 2016;

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DOI: 10.1542/hpeds.2016-0032 originally published online October 7, 2016;

The online version of this article, along with updated information and services, is located on the World Wide Web at:

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