

Features

Your Child Does Not Have Chronic Lyme Disease: A Commentary on Communication, Beneficence, and Consent

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ABSTRACT

Careproviders who are appropriately acting in pediatric patients' best interests will help them to achieve a developmentally appropriate understanding of their condition, outline the expected outcomes of their tests and treatments, assess their understanding, and solicit their willingness to accept the proposed treatment.

Physicians and those who care for children must "attend to possible abuses of 'raw' power over children when ethical conflicts occur."¹ As a hospital physician engaging in the care of children and adolescents, abuses of power might be difficult for me to identify and even more difficult for me to act upon, but are easy for me to palpate.

Some time ago, I was caring for a 15-year-old adolescent female with a prior diagnosis of chronic systemic pain and chronic abdominal pain. She had been in pain programs at reputable institutions in the past and had "graduated." Despite this, she experienced an acute worsening of her symptoms and came to our facility needing help. Almost immediately her family's struggle to manage her pain and the impact on their lives became clear to me and the inpatient team. She was home schooled. She had

anxiety and depression. She had received a PICC (peripherally inserted central catheter) line from a naturopathic family medicine provider and received a number of medications that were out of my lexicon: several months of high-dose vitamin C, many courses of intravenous antibiotics for her recent diagnosis of chronic Lyme disease, and numerous oral supplements. While our standard of care for PICC lines is in the order of weeks, hers had been in place for nine months.² It was miraculous that she had not yet experienced a complication like line fracture, bacteremia, or clot formation.³ It was clear that her family had weighed appropriate therapies and had chosen those they thought best for their daughter. With great distress at seeing nonstandard care, and disagreement with the patient's diagnosis, I took the opportunity to educate the patient and family about the known dangers of indwelling central intravenous access, and encouraged removal of the line as soon as possible. The family did not agree. In this situation, just who was abusing their raw power over this child?

The American Academy of Pediatrics (AAP) guideline, "Informed Consent, Parental Permission, and Assent in Pediatric Practice," insists that patients participate in decision making "commensurate with their level of development."⁴ Generally speaking, all patients or their surrogates have a right to decide, after consultation with their physician, whether they will or will not accept a particular

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medical intervention. For adolescents, this includes the power of assent; research indicates that their decision-making skills are mature by approximately age 14.⁵ Careproviders who are appropriately acting in pediatric patients' best interests will help them to achieve a developmentally appropriate understanding of their condition, outline the expected outcomes of their tests and treatments, assess their understanding, and solicit their willingness to accept the proposed treatment.⁶ Like many adolescent patients like this patient, physicians often direct their conversations to the patients' caregivers, rather than to the patients, or conversations with patients are then deferred to their caregivers. If physicians are

massage, cannabinoids, healing touch, and acupuncture; however, this treatment seemed inappropriate. In 2000, the AAP created the Task Force on Complementary and Alternative Medicine (CAM).⁹ Since that time the prevalence of the use of CAM has been studied: one study reported that 61 percent of adults in the United States used CAM,¹⁰ another study reported that fewer than 50 percent of children in the U.S. with "chronic, recurrent, or incurable conditions" used CAM.¹¹ The most common reasons for using CAM cited included word of mouth, the belief that the treatments were effective, fear of adverse drug events, dissatisfaction with conventional medicine, and the need for more personal attention

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to follow the principal of beneficence, we should acknowledge that parents' refusal of treatment or parents' insistence on a particular therapy are not in our patients' best interests, and we have a duty to act to preserve their best interests.⁷ For my patient, this meant consultation with my institution's pain specialist, a conversation with the patient's prescribing provider, and sharing information with the patient's family. I was surprised to hear that the prescribing provider vehemently disagreed with my recommendation to remove the patient's PICC line.

When considering alternative therapies, physicians are not ethically obligated to offer an intervention that is medically futile, even if it is requested by the patient; however, open conversation is encouraged. I wondered whether my patient had received appropriate consent or assent for costly (according to her parents, more than \$1,000) laboratory testing and intravenous therapies, with promised effectiveness. After all, my patient continued to have pain. If I practiced medical "pluralism," that is, "respect despite honest disagreement" regarding a treatment practice, I would support my patient's autonomy to make treatment decisions.⁸ To do this would be difficult. Within my present practice, I have developed appreciation for many alternative therapies including chiropractic, aromatherapy,

from careproviders.¹² Given patients' ready access to valid as well as inaccurate information online, and rapidly growing social networks, those of us practicing Western medicine may be doing our patients a disservice. We may be so consumed with data entry and staying current on clinical care that we may have missed developments in the CAM field.

Pediatricians should remain abreast of resources such as the AAP's 2001 policy, "Counseling Families Who Choose Complementary and Alternative Medicine for Their Child with Chronic Illness or Disability."¹³ It is our responsibility, too, to know that, as of 2006, less than 5 percent of CAM research was dedicated to pediatrics.¹⁴ We shouldn't ignore the fact that very few CAM providers undergo extensive education or training specific to pediatrics.¹⁵ For example, in a four-year CAM training program, just one rotation, several weeks in duration, may focus on pediatrics. As with our concern for medical abuse and neglect, our eyes should be open to "medical negligence" when other careproviders are providing therapy that does not meet the standard of care, and they may be committing fraud and abuse by charging for therapies that have been deemed to be medically unnecessary.¹⁶ Our duty as physicians to fully inform our patients includes describing the acuity of their illness, our ability to cure their dis-

ease with conventional therapies, the degree of invasiveness of any given procedure, the toxicities of conventional therapy, and the evidence for the safety and/or efficacy of CAM; and to assess patients' family members' understanding of the risks and benefits of treatments. Our professional duty is always to treat the patient. I wondered whether my outpatient colleague had fulfilled his or her duty.

I didn't believe my patient had chronic Lyme disease, but I did believe I could help her, after reading of a recent article in the Centers for Disease Control and Prevention's publication Morbidity & Mortality Weekly Report, which noted the complications of treatment of this entity and included hotly debated commentaries.¹⁷ I recalled the personal and professional challenge of treating my patient.¹⁸ Despite our discussions, she left the hospital with her PICC line in place and with a plan for follow up with her naturopathic careprovider, as requested by her family. It was clear to me that this careprovider did not appreciate my willingness to question diagnoses, treatments, and interventions that I thought were unnecessary for the patient. For a brief time, though, she was my patient. I hope I broadened her treatment options and bolstered her decision-making capacity. As her pediatrician, it was my legal and ethical duty to appreciate, support, and defend her competency, no matter how "alternative" her treatment course had been.

MASKING OF THE CASE

Details of this case have been altered to protect the identity of the patient and family.

NOTES

1. AAP, "Guideline on Informed Consent, Parental Permission and Assent in Pediatric Practice," *Pediatrics* 95, no. 2 (February 1995): 314-7; <http://pediatrics.aappublications.org/content/96/5/981>.

2. N. Moureau and V. Chopra, "Indications for peripheral, midline, and central catheters: summary of the MAGIC recommendations," *Journal for the Association for Vascular Access* 21, no. 3 (2016):140-8; A. Kovacich et al., "Peripherally Inserted Central Venous Catheter Complications in Children Receiving Outpatient Parenteral Antibiotic Therapy," *Infection Control & Hospital Epidemiology* 37, no. 4 (2016): 420-4; K. Jumani et al., "Risk factors for peripherally inserted central venous catheter complications in children," *JAMA Pediatrics* 167, no. 5 (2013): 429-35; S. Advani et al., "Central-line associated blood stream infection in hospitalized children with peripherally-inserted central venous catheters: extending risk analyses outside the intensive care unit," *Clinical Infectious Diseases* 52, no. 9 (2011): 1108-15.

3. Ibid.

4. AAP, "Guideline on Informed Consent," see note 1 above.

5. P. Grootens-Wiegers, I.M. Hein, J.M. van den Broek, and M.C. de Vries, "Medical decision-making in children and adolescents: developmental and neuroscientific aspects," *BMC Pediatrics* 17 (2017): 120; doi: 10.1186/s12887-017-0869-x.

6. Ibid.

7. C. Cummings and M. Mercurio, "Ethics for the Pediatrician," *Pediatrics in Review* 31, no. 6 (June 2010): 252-6.

8. F.J. Kaptchuk and F.G. Miller, "What is the best and most ethical model for the relationship between mainstream and alternative medicine: Opposition, integration, or pluralism?" *Academic Medicine* 80, no. 3 (2005): 286-90.

9. K.J. Kemper, S. Vohra, R. Walls, and the Task Force on Complementary and Alternative Medicine, the Provisional Section on Complementary, Holistic, and Integrative Medicine, "The Use of Complementary and Alternative Medicine in Pediatrics," *Pediatrics* 122, no. 6 (December 2008): 1374-86; <http://pediatrics.aappublications.org/content/122/6/1374>.

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11. K.J. Kemper, "Complementary and alternative medicine for children: does it work?" *Western Journal of Medicine* 174, no. 4 (April 2001): 272-6.

12. Kemper, Vohra, Walls, and the Task Force, "The use of complementary," see note 8 above.

13. AAP Committee on Children with Disabilities, "Counseling Families Who Choose Complementary and Alternative Medicine for Their Child With Chronic Illness or Disability," *Pediatrics* 107, no. 3 (1 March 2001): <http://pediatrics.aappublications.org/content/107/3/598.info>.

14. Kemper, Vohra, Walls, and the Task Force, "The use of complementary," see note 9 above.

15. M.S. Wetzel, D.M. Eisenberg, and T.J. Kaptchuk, "Courses involving complementary and alternative medicine at US medical schools," *Journal of the American Medical Association* 280, no. 9 (1998):784-7.

16. Kemper, Vohra, Walls, and the Task Force, "The use of complementary," see note 9 above.

17. N.S. Marzec et al., "Serious Bacterial Infections Acquired During Treatment of Patients Given a Diagnosis of Chronic Lyme Disease—United States," *Morbidity and Mortality Weekly Report* 66, no. 23 (16 June 2017): 607-9.

18. S. Shore, "Letter to the Editor," <https://www.ilads.org/wp-content/uploads/2018/03/6-16-2017-letter-to-the-editor-MMWR.pdf>.