

Book Review

The importance of listening in pediatric care

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Whiting V, Whiting K (2011). *In pain we trust: a conversation between mother and son on the journey from sickness to health*. New York: Blooming Twig Books, 252 pp. ISBN 978-1933918884 (Paperback: \$18.95 USD).

In pain we trust is a memoir written jointly by a mother and son, Vicki and Kevin Whiting, which chronicles their efforts to navigate the American health care system in search of treatment for Kevin's weight loss, nausea, and abdominal pain. The story is a journey for a diagnosis to explain Kevin's symptoms and ultimately to get effective treatment. In short, although Kevin had experienced trouble gaining weight and intermittent abdominal pain throughout his life, a more urgent medical crisis emerged at age 13 when he was unable to keep food down and lost 20 pounds. At that time, an inpatient hospitalization was recommended to expedite a thorough diagnostic workup. Kevin was labeled by an attending physician as anorexic to describe his lack of appetite, which was subsequently interpreted by his treating health care team as anorexia nervosa. Despite his denial of psychiatric illness, Kevin was sent home on a regimen of psychotropic medications to treat anxiety and mood symptoms that were presumed to underlie his weight loss and abdominal pain. Over the next several months, Kevin became unable to participate in his daily life due to his medical condition and he began to contemplate suicide. Kevin's mother was spurred into further action and sought out a variety of specialists, including visiting physicians in Australia during a family vacation. Eventually, their search led them to a local

colorectal surgeon who was also a family friend. Over one year after Kevin's initial hospitalization, this surgeon was the first person Kevin and his family felt had truly listened to the entire story of his medical condition. The meeting with this surgeon led to diagnostic imaging that revealed Superior Mesenteric Artery Syndrome (also called Wilkes Syndrome), a rare congenital anomaly where the mesenteric artery flattens the small intestine and causes intestinal blockage and abdominal pain. Kevin underwent surgical intervention to bypass the blockage in his small intestine, and the book concludes with Kevin working towards recovering his intestinal motility and reclaiming his life.

This book is well-written, easy to read, and engaging. Chapters are alternately authored by Vicki and Kevin, which allows the reader to appreciate the similarities and differences between how mothers and their children may experience living with and recovering from a pediatric chronic illness. Vicki provides a candid description of her reaction to Kevin's health status, her interactions with the health care system, and the impact of Kevin's illness on her marriage and her other children. Similar to many parents who have a child with a chronic illness, Vicki focused all of her energies on caring for her son and meeting her work commitments in order to maintain her family's health insurance coverage. Vicki recounts growing emotionally distant from her husband in the months spent searching for a cure for Kevin's illness. She describes taking pride in being Kevin's primary caregiver and consequently criticizing her husband's attempts to participate in Kevin's

medical care. Over time, Vicki and her husband stopped communicating about Kevin's illness along with all other stressful aspects of their family life. Vicki discusses the difficulty she faced in acknowledging the emotional toll that caring for Kevin had taken on herself and her husband, and describes recognizing the impact of Kevin's illness on her marriage as a key step in enabling them to work together to find a cure. She also describes neglecting her other two children, at one point becoming so overwhelmed at the prospect of missing a dance class (her one indulgence) that she threw her older son out of the car in the middle of a snowstorm. Vicki's frank perspective on her own experience balancing her work and home life in the context of caring for Kevin is informative for health care providers to understand the tremendous impact and burden that parents experience caring for ill children, and may be of some comfort to other parents of children with chronic illness.

Vicki and Kevin's story also highlights the role of mental health professionals in the evaluation of medically ill children. During his initial hospitalization, Kevin and his mother write about daily bedside visits during which psychologists and social workers repeatedly asked him about his body image, his sexuality, whether he had been abused, and whether he felt stressed, anxious, or depressed. Kevin describes feeling helpless during these interactions, as he repeatedly denied their concerns but was faced with the dissatisfaction of his health care team as they attempted to formulate a psychological explanation for his medical condition. When Vicki attempted to advocate for her son by assuring the health care team that anxiety was not the cause of his medical problems, she was labeled as overly involved and a part of the problem. This experience highlights the risks associated with overinterpreting psychiatric symptoms when the cause of a patient's medical condition is unclear. In pediatric medical settings, clinical interviews are often conducted when patients are particularly vulnerable (i.e. not feeling well, unable to get out of bed, and poorly equipped to self-advocate). There is also an inherent inefficiency in information gathering as new providers are consulted to evaluate a child in the hospital. This story is a good reminder that objectivity is needed in the context of vague

medical symptoms and that a serious consequence of overinterpretation of psychiatric symptoms is inappropriate medication recommendations. For example, Kevin was discharged on a regimen of antianxiety and antidepressant medications despite the fact that he denied any anxiety or mood symptoms.

Despite these strengths, the story that is told in this book may not be particularly helpful to share with parents of children with chronic pain for several reasons. *In pain we trust* is a story about a child who has a very rare and difficult to diagnose medical condition. The focus of this book is on the family's search for the cause of Kevin's pain and weight loss, and his subsequent recovery once the cause was identified and the appropriate treatment was implemented. A primary take home message of this book is that parents who work hard enough to advocate for their child will eventually find a doctor who is willing to order all possible diagnostic tests until a medical diagnosis is identified and treated. While in this particular situation, this advocacy was important for ultimately leading to Kevin's cure and recovery, for most children with chronic pain, the search for a cure is unnecessary and often delays appropriate treatment. This message directly contradicts what we ask of families of children with chronic pain, which is to abandon the search for a medical diagnosis and focus instead on restoring their child's ability to participate in their daily life. Parents may come away from reading this book with ideas that undermine essential principles of chronic pain treatment, thereby serving as a barrier to care rather than an aide in recovery. While we would not recommend this book to families of children with chronic pain, parents of children with other types of chronic illness may benefit from reading this book as a way to normalize their own experience living with a child who has a serious medical condition, managing the health care system, and balancing commitments at work and home.

Notably, this book may be most appropriate for health care professionals. In fact, a letter Vicki wrote to hospital administrators about her experience advocating for her son inspired her to write this book. A second take home message in this book is that Kevin may have been spared significant emotional and physical suffering if the

health care team at his initial hospitalization had not persisted in searching for a psychological explanation for his symptoms and instead referred him to appropriate specialists. The book closes with a description of a meeting between Vicki and the Risk Manager at Kevin's local hospital to determine what changes needed to be made in their health care system based on the poor outcome of that hospital stay. Health care providers may benefit from reading this book as a way to understand the importance of listening in providing high-quality care to pediatric patients and their families.

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