"An Opportunity to Fail": An Examination of Bias in Pediatric Residents' Case Presentations

Hellen Ransom and Ronald M. Perkin

ABSTRACT

This article presents an examination of the cases from 2002 to 2015 during the Pediatric Chairman's Ethics Rounds at East Carolina University's Brody School of Medicine, with specific attention placed on bias and the day-to-day interactions that were identified by our residents. The themes and ethical issues included: pediatrics at the end of life, neonatal issues ranging from the fetus as a patient to the first few months after birth, maternal-fetal issues, parental decision making, adolescent decision making, determining the appropriate decision maker, abuse/neglect, organizational ethics, and professionalism. Figure 1 summarizes the number of cases and the primary ethical issues that were presented during this 13-year time frame. While most of the themes and ethical issues were discussed in detail when they were presented, it was not until we re-examined these cases that we noticed the undercurrent of themes that may have contributed to the overall moral distress involved in one case. Professionalism was initially indicated as a central theme by residents in 32 cases, and, upon further examination, this number increased to 86. While the professionalism issues varied in scope, one of the subtle components that impacted the residents' case presentation was the concept of bias.

PRESENTATION OF FINDINGS

Since 2002, the Pediatric Department at East Carolina University's Brody School of Medicine has worked in collaboration with its Bioethics Department to provide a space for residents to share and reflect on ethical issues in the form of the Pediatric Chairman's Ethics Rounds. Clinical cases were presented with an emphasis on the ethical dilemmas in healthcare, simulating what might occur in an oral case presentation. Rounds consisted of residents, nursing and medical students, hospital clergy, hospital administrators, and other members of the healthcare team. After an initial case description, the resident in charge of the case presented questions to the audience, to provide a forum for reflective discussion of ethical dilemmas. Commentary was generated and supported by Ron Perkin, MD, then Chairman of the Pediatrics Department, and a faculty member from Brody School of Medicine's Department of Bioethics and Interdisciplinary Studies. Residents presented 150 cases for review. Special attention was paid to the primary and secondary issues that were identified by the residents. Surprisingly, 21 percent of the cases included some type of bias, directed at either the patient/family or the resident.

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Factors such as disparities and discrimination are often seen as immediate connecting factors to what ascribes to bias. Biases are based on implicit and explicit thoughts, displayed through various actions, and could be interpreted as prejudging. In *Seeing Patients: Unconscious Bias in Health Care,* White and Chanoff discuss the concept of unconscious bias, indicating that we all have behaviors that can greatly influence, and at times interfere with, communicating with patients.[1] It is in the latter part of this description the trouble lies for a vulnerable group such as pediatric patients. At the stage of residency, physicians have their own views about what health and healthcare should not entail. These perceptions are influenced by culture, medical education, and understandings of how interactions should take place within pediatric medicine. These assumptions routinely develop, or at least universally risk development, into biases that can become part of the clinical experiences of patients and families.

It is within the common daily interactions that residents are faced with situations for which they may not be adequately prepared. While pediatric residency programs have worked diligently at incorporating and training residents in ethics,[2] there is still room for improvement.[3] Resident education has long been fraught with seeking advancements to improve the development of freshly minted physicians in training. The day-one standards of residents' expectations have increased over the last eight years, with an emphasis on professionalism.[4] As patient populations become more diverse, resident education has recognized the need for effective communication and compassionate understanding for those who seek care. We recognize this as a need to address, improve, and acknowledge the impact of bias in patient care.

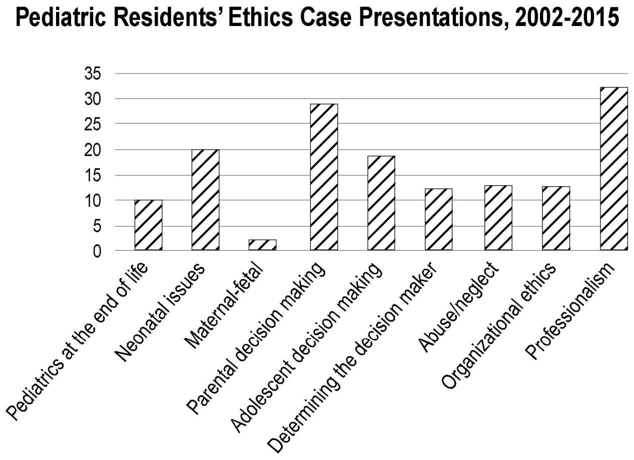

FIGURE 1.

We will examine two cases in which biases influenced the ways that pediatric patients received effective medical treatment. These cases were selected because of the subtle presentation of bias. This is important because implicit bias is difficult to detect, and these cases highlight the impact of judging the parents of pediatric patients. Most of the case information is described in the residents' words, because we wanted to emphasize the nature and spirit in which the cases were initially presented.

CASE APPLICATION OF BIAS IN PEDIATRICS

Case One

S.H. was a four-month-old female infant with history of intrauterine growth restriction (IUGR), congenital limb anomalies, eventration of her diaphragm, a maternal history of human immunodeficiency virus (HIV) with noncompliance with zidovudine and maternal cocaine abuse, who was transferred from a community hospital to a tertiary pediatric intensive care unit.

Shortly after arrival, the patient began to experience desaturation episodes that required bag mask ventilation. During these events the mother was at the bedside, assuming a withdrawn role. Initially, the mother was asleep and did not wake during the commotion, even when the patient was hand ventilated. Staff woke the mother multiple times to inform her about the situation, and each time she went back to sleep. She was awakened again and moved to a chair where she began watching television. Again, she fell asleep while the patient was managed for another episode of acute respiratory failure.

After stabilizing the patient, S.H. was transferred to the transitional care unit (TCU) service, where she recovered post tracheostomy, placement of a gastronomy tube, and repair of the diaphragm. S.H.'s status did improve, but she was technology dependent. Staff members were concerned that the mother was not involved in S.H.'s care. She called out when the patient cried or had a dirty diaper. When S.H.'s mother was in the baby's room, she was usually on the phone and interacted very little with her daughter.

The patient had three siblings: a nine-year-old sister, and a seven and a three-year-old brother. The two eldest children were in their grandmother's custody. The grandmother was given custody of the children by the mother because the mother was too young to take care of them.

The primary questions with this case center on the distinction between best interest and parental authority: was S.H.'s mother the appropriate decision maker, and, upon discharge, would the mother provide the best care for S.H.? In this case, the resident was faced with the balancing act of trying to care for a medically complicated child amid an equally complicated social situation. The reader can tell by the way that the resident highlighted S.H.'s mother's lack of involvement in the care of her infant that there was some level of bias against the mother. Unfortunately, S.H.'s positive cocaine test and the fact that her siblings lived with her grandmother only added to the perception of the mother as someone who had her decision-making ability questioned in the past. These judgmental labels only condemned S.H.'s mother before she had a chance to show what type of parent she would be.

Given the complexities that this case presented, the medical team sought the assistance of the local Child Protective Services (CPS). After an initial investigation that included talking to the medical team and family members, CPS gave an assessment that startled the medical team and the resident: "You must give S.H.'s mother an opportunity to fail." These words were hard to accept, because they required relying on a caretaker that the team perceived as disengaged and inept to care for such a medically complicated child. While both the resident and the CPS agent were thinking of S.H.'s best interest, they had different approaches to this goal. The CPS agent came into the situation with a fresh set of eyes, was able to slow down the fast pace, and see S.H.'s mother as just that: her mother. The key to addressing bias in this case was giving residents an opportunity to slow down, utilize additional resources, and evaluate alternative options with the assistance of a CPS consult. In this case specifically, it was important to examine who would care for S.H., and if removing her from the care of her mother was the best option. While the resident in this case may not have been pleased with what the CPS agent stated, the consultation with CPS did provide a moment for the medical team to think about how they might have projected their biases against S.H.'s mother. Residents are trained to repair what is broken, and, in this case, not only was S.H. in need of medical assistance, but the medical team perceived her mother as being in need of rehabilitation. Moreover, this presented an opportunity to review what some may categorize as a nonsolution, that is, removing S.H. without any consideration of the real-world options and how they would affect S.H.

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Case 2

C.M. was a two-month-old male with trisomy 13 who was transferred from an outside hospital so that his mother could be closer to her extended family. He was born via c-section at 32.4 weeks. During the pregnancy, the diagnosis of trisomy 13 was made, and C.M.'s prenatal ultrasound revealed multiple intracardiac echogenic foci, mesocardia, and cerebellar hypoplasia, among other abnormalities. After these results during the first-trimester screening, the parents were told that C.M.'s diagnosis was incompatible with life. Historically, trisomy 13 was "designated as [a] lethal"[5] diagnosis, in part because of the chromosomal impact on the development of organ function, "severe intellectual disability, and physical abnormalities."[6] C.M.'s parents heard much of the same "lethal" language (information about the poor prognosis, quality of life, and an earlier recommendation to consider terminating the pregnancy), which had the potential to distract and harm communication.[7] The parents continued with the pregnancy, although they understood C.M.'s poor prognosis. At birth, the baby was intubated for respiratory distress. Thereafter, he had several failed extubations, and ultimately required a tracheostomy. Prior to admission, C.M. had had five septic work ups, and had required multiple antibiotics for suspected sepsis and urinary tract infections, as well as several intubations, cardiac catheterization, and bronchoscopy.

The patient was admitted to the pediatric intensive care unit (PICU) when he was eight weeks old, at the request of his parents. His mother was especially interested in the care coordination provided by the Center for Children with Complex and Chronic Condition (C5) team. C.M.'s parents were always attentive and very involved in his care. They wrote the number for his day of life and a daily motivational phrase on colorful papers for the bedside. They wore t-shirts displaying support and optimism when they would visit, and often decorated his room. C.M.'s mother also created a Facebook page about him, where she often posted updates about his medical status, and asked for prayers and support. The page had a growing number of followers, ultimately reaching hundreds of thousands. C.M.'s mother claimed that she had met the mother of a child with trisomy 13 who was now eight years old and followed by a very dedicated doctor at C5 clinic, and that if C.M. had made it this far, he had already defied the odds. A multidisciplinary family meeting was held where the plan of care and parent's expectations were discussed. C.M.'s mother stated that "they were not giving up as long as C.M. is willing to fight," and that they "just wanted to give him the best chance and best quality of life." Their goal was to "take him home for as long as they could, once he was stable."

C.M. remained rather stable for the following two weeks and was eventually transferred to the TCU. He later became acidotic (high blood acidity leading to poor cardiopulmonary function) and oliguric (low urine output), so he was transferred back to the PICU. An abdominal ultrasound showed ascites (abnormal accumulation of fluid in the abdomen), but no evidence of perforation. The pediatric surgery team evaluated the patient and he was diagnosed with peritonitis. As the weeks progressed and C.M.'s respiratory status worsened, a family meeting was held, which included the PICU team, a pulmonologist, pediatric surgeon, case manager, psychologist, and the nursing staff caring for C.M. After the medical team updated C.M.'s parents about his medical status, his mother stated, "we want to fight for him as long as he is willing to fight." She further emphasized that "as long as interventions are being offered, there is hope." She shared that she and C.M.'s father knew how sick he was, but they were not willing to give up yet, and that they would need assistance in making the decision "when enough is enough."

This case was presented by a different resident. Just as in the previous case, this resident's tone revealed a sense of bias, but this time it was bias in favor of the family and the patient. The language that was used to describe trisomy 13 and C.M.'s condition falls in line with "lethal" language. As Koogler and colleagues point out, connecting quality of life and the language used to describe treatments can be dangerous because parents' decisions may be influenced by how their child's condition is presented to them.[8] This case is interesting because C.M.'s family reminded the medical team of how they defined C.M.'s quality of life, and his family made what they thought to be the best decisions based on their own values, and not on the "lethal" language of trisomy 13. One could argue that the medical team's bias was in place before C.M. was born, due to the labels and stigma attached to trisomy 13. The recommendation that C.M.'s mother abort, and the descriptions used to chart C.M.'s hospitalizations identified C.M. by diagnostic categories, and not according to how his family saw him.

While C.M.'s parents may not have known that they were doing so, they addressed the bias displayed regarding their son. By wearing t-shirts and posting their story online, C.M.'s family presented a constant reminder that their son was a person, and not merely his disease. Bias in language is hard to detect or directly combat, especially in medicine, because it can be grouped with the nuances used to describe medical care. Nonetheless, residents and medical teams must become sensitive to the labels they use, and think about how they describe patients. A fair question to ask during plan of care meetings is: "Are you describing the disease or the patient?"

SUMMARY

Often with the rigors of medicine, little opportunity is provided to take stock of one's personal inventory and learn how to deal with ethically challenging clinical cases and how to deal with the associated stress and long-lasting effects, that is, moral distress and moral residue. Over the course of 13 years, our residents have brought forth cases that they found not only interesting, but that presented them with moral dilemmas in various clinical settings. When coupled with the questions and the back stories that our residents provided, these cases speak to the morally complex issues that many who attend these conferences have not been given the opportunity to articulate.

The basic principles of medical ethics provide a solid foundation from which many new residents seek guidance during complicated and morally conflicted times. Such a foundation becomes increasingly important when residents do not have a strong background in such morally fraught and medically complicated cases. While they may have a basic familiarity with the principles of autonomy, beneficence, nonmaleficence, and justice, often it is not until their residency that they get an opportunity to apply the principles to a case beyond a textbook. It is during these times that the realities of medicine have the potential to conflict with the static, and, most problematically at times, irreconcilable nature of ethical dilemmas. The themes examined here go beyond the basic concepts of medical ethics and allow residents to reflect on the ethical issues presented in each individual case.

PRIVACY

Details of the cases have been altered to protect the identities of patients and family members.

NOTES

1. A.A. White and D. Chanoff, *Seeing Patients: Unconscious Bias in Health Care* (Cambridge, Mass: Harvard University Press, 2001), 301.

2. H.J. Mulvey, E.A. Ogle-Jewett, T.L. Cheng, and R.L. Johnson, "Pediatric residency education," *Pediatrics* (2000): 325.

3. W.R. Waz and J. Henkind, "The adequacy of medical ethics education in a pediatrics training program," *Academic Medicine* 11 (1995): 1041.

4. M.A. Zafar, T. Diers, D.P. Schauer, and E.J. Warm, "Connecting resident education to patient outcomes: the evolution of a quality improvement curriculum in an internal medicine residency," *Academic Medicine* 10 (2014): 1342.

5. S. Haug, M. Goldstein, D. Cummins, E. Fayard, and T.A. Merritt, "Using patient-centered care after a prenatal diagnosis of Trisomy 18 or Trisomy 13," *JAMA Pediatrics* 4 (2017): 382.

6. Lister Hill National Center for Biomedical Communications, U.S. National Library of Medicine, National Institutes of Health, and Department of Health and Human Services, "Trisomy 13," Genetics Home Reference, 2013, *https://ghr.nlm.nih.giv/condition/trisomy-13.*

7. A. Kidszun et al., "What if the prenatal diagnosis of a lethal anomaly turns out to be wrong?" *Pediatrics* 5 (2016): 2.

8. T.K. Koogler, B.S. Wilfond, and L.F. Ross, "Lethal Language, Lethal Decisions," *Hastings Center Report* (2003): 37-41.