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The Angry Amish Grandfather: Cultural Competence and Empathy: A Case Commentary

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ABSTRACT

Crosscultural encounters are common in the delivery of healthcare, and cultural differences may contribute to misunderstandings and ethical conflict. Encounters between members of the Amish ethno-religious group and modern, science-based healthcare providers hold a high potential for misunderstanding and conflict because the Amish stridently maintain a countercultural outlook and they approach such encounters with suspicion and anxiety. This commentary on the case presented by Amy E. Caruso Brown, MD,[1] involving a grandfather's resistance to treating a child with leukemia commends this physician for successfully managing the case and deriving important insights from reflection upon it. It argues, however, that the level of conflict most likely would have been reduced if the care team had made more of an effort to listen to the grandfather and acknowledge the emotional trauma he had suffered.

In modern, culturally diverse societies, cross-cultural encounters in healthcare are inevitable. In the vast majority of such encounters, the provision and reception of appropriate care occurs without incident. In a small percentage of such encounters, however, cultural differences lead to misunderstandings, hurt feelings, and occasionally outright conflict. In the late 1970s and early 1980s, recognition of the potential for cultural differences to lead to conflict or to otherwise interfere with the provision of healthcare led to the development of an emphasis on cultural competence. This emphasis has since become a basic element in the training of healthcare providers, especially nurses.[2] Its value to healthcare ethics consultants and committees has also been promoted in the literature.[3]

The case presented by Amy E. Caruso Brown is an excellent example of ethical conflict in which cultural differences between healthcare providers and the patient and his family appear to play a major role. Brown and her colleagues are to be commended for their successful management of this case, both medically and ethically, which ultimately led to a good outcome. Brown is also to be commended for taking advantage of the opportunity to reflect upon and share the case in order to gain understanding that may be useful in future encounters with Amish patients.

The Amish are the most widely known of a number of ethno-religious groups which may be classified as "Plain Anabaptists." Plain Anabaptists share several salient characteristics, including plain dress, resistance to some forms of modern technology, close community ties, and conscious efforts to remain separate from the non-Plain Anabaptist world.[4] Plain Anabaptists are found throughout North America, with concentrations in certain regions, including

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upstate New York, Pennsylvania, Ohio, and Indiana.[5] There are actually more than 40 distinct groups that identify as Amish, with a total population of around 300,000. All trace their heritage back to early Mennonites in Germany and Switzerland during the 16th century. The Amish are the descendants of those Mennonites who followed a leader known as Jakob Ammann in the late 17th century. On the whole, they tended to be more resistant to inculturation than other Mennonites. Today, the degree of Amish resistance to the larger culture and its technologies range along a spectrum, from the most resistant Schwartzentruber Amish to the far more open Beachy Amish.[6]

As evidenced by this case, the Amish are not opposed to seeking modern, scientifically based medical treatment. However, they often do so only after availing themselves of other options, including various forms of complementary and alternative medicine (CAM) and faith healing.[7] It is not unusual, therefore, for Amish patients to be quite ill or injured when they first seek treatment from a physician or hospital. It is also not uncommon for Amish to express or exhibit reluctance toward or outright refusal of recommended tests or treatments, especially those that are expensive or that have only a slim chance of success.[8]

In this case, the reluctance to pursue treatment for a three-year-old Amish boy who presented with symptoms of acute myeloid leukemia raised strong ethical concerns among the medical staff. Refusal of treatment for pediatric patients is one of the most common triggers of ethical conflict involving the Amish, and similar scenarios have appeared previously in ethics literature.[9] What distinguishes this case, as Brown notes, is the seemingly unprovoked and ardent adversarial position taken early on in the encounter by the maternal grandfather of the patient. Brown and her team were right to conclude that this was an atypical reaction and to suspect that it was idiosyncratic, not cultural in its origin.[10]

Brown's analysis also explored questions around the deferment of decision-making authority to a grandparent and the suspicion by some of the treatment team that the child's parents and other family members might have been sending nonverbal signals indicating disagreement with the maternal grandfather. As acknowledged in Brown's case analysis, any competent adult may defer decision-making authority to another competent adult. This is ideally done explicitly and documented. In this instance, the lack of overt objections seems to have served as sufficient evidence of a willingness to defer.

With regard to the possibility that other family members were sending nonverbal signals of disagreement, one should be cautious about reaching such a conclusion and especially cautious about acting upon it. First, the situation is obviously ripe for members of the care team to project their own feelings onto members of the Amish family. Second, cultural barriers can make the interpretation of nonverbal communication quite difficult. Finally, a desire for the child to receive treatment and respect for the authority of an elder in the family can coexist as first and second order desires.[11] In Amish culture, which encourages an attitude of *gelassenheit,*[12] or surrender to authority within the community, it is conceivable that one might *wish* for the child to receive treatment but nonetheless *will* compliance with the decision of the grandfather.

Brown reached a number of sound conclusions about what might have been done differently and what may be learned from the case. She noted that the failure to pursue the grandfather's initial request to involve community elders in a discussion was a "lost opportunity." If, as suspected, the reaction of the grandfather was idiosyncratic rather than a genuine expression of cultural values, a meeting with the elders would have provided the opportunity not only to determine this, but also to help persuade the grandfather to be more cooperative. Brown also came to recognize that "more intentional communication" might have been beneficial and acknowledged the need for patience on the part of careproviders in order to build trust.

In particular, such patience might have manifested itself in a willingness to listen to and accept the maternal grandfather as someone who was still suffering from his own prior emotional trauma. Ethics must always include a sincere effort to see the situation from another's point of view. The grandfather believed that he and his community had been harmed and disrespected[13] in a previous encounter with science-based healthcare, and this may indeed have occurred. The scenario described in the first endnote of Brown's article, in which a woman from this community was resuscitated and placed on life support for a week without reasonable hope for meaningful recovery, is troubling and not implausible. One should be able to empathize with the grandfather's fear that similarly futile treatment might be forced upon his family. A willingness to listen, to acknowledge the unfairness of the prior situation (at least as the grandfather describes it), and to reassure the grandfather that he and his community are respected, may have lessened the anxiety all around.

So we may add to Brown's list of valuable insights from this case the following: when we meet with an unexpected, highly emotional reaction, either in the delivery of healthcare or in the course of ordinary life, most often there is a story lurking in the background. If one wishes to keep the reaction from developing into full-blown conflict, it is useful to develop the skills necessary to coax out the story, listen non-defensively, and respond with appropriate empathy. In the end, this case may have been less about a conflict between values than it was about a need to recognize and respond to the grandfather's suffering.

NOTES

1. A.E.C. Brown, "At the Intersection of Faith, Culture, and Family Dynamics: A Complex Case of Refusal of Treatment for Childhood Cancer," in this issue of *JCE,* 28, no. 3 (Fall 2017).

2. For an account of the development of the field of cultural competence in healthcare, see S. Saha, M.C. Beach, and L.A. Cooper, "Patient Centeredness, Cultural Competence and Healthcare Quality," *Journal of the National Medical Association* 100, no. 11 (November 2008): 1278-80.

3. B. Gray, "Clinical Ethics, Cultural Competence and the Importance of Dialogue: A Case Study," *Journal of Clinical Research and Bioethics* 7 (2016): 256; J.J. Voight, "Cultural Competency—The Caregiver Connection," *Bioethics Forum* 19, no. 1/2 (2003): 17-23; D.F. Pacquiao, "Ethics and Cultural Diversity: A Framework for Decision-Making," *Bioethics Forum* 17, no. 3/4 (2001): 12-7.

4. L. Graham and J.A. Cates, "Health Care and Sequestered Cultures: A Perspective from the Old Order Amish," *Journal of Multicultural Nursing and Health* 12, no. 3 (2006): 60-3; J.A. Brewer and N.M. Bonalumi, "Cultural Diversity in the Emergency Department: Health Care Beliefs and Practices among the Pennsylvania Amish," *Journal of Emergency Nursing* 21, no. 6 (1995): 495; C. Dellasega, J.E. Hupcey, and K. Fisher, "Culturalizing Health Care for a Culturally Diverse Population: The Amish," *Clinical Excellence for Nurse Practitioners* 3, no. 1 (1999): 10.

5. C. Anderson, "Who are the Plain Anabaptists? What Are the Plain Anabaptists?" *Journal of Amish and Plain Anabaptist Studies* 1, no. 1 (2013): 26-71; C. Anderson and J.F. Donnermeyer, "Where Are the Plain Anabaptists?' *Journal of Amish and Plain Anabaptist Studies* 1, no. 1 (2013): 20.

6. J.A. Cates, *Serving the Amish: A Cultural Guide for Professionals* (Baltimore: Johns Hopkins University Press, 2014), 5-10.

7. D. Garrett-Wright, M.S. Jones, and M.E. Main, "Anabaptist Community Members' Perceptions and Preferences Related to Healthcare," *Journal of Amish and Plain Anabaptists Studies* 4, no. 2 (2016): 193-4; Brewer and Bonalumi, "Cultural Diversity," see note 4, p. 495.

8. S.M. Weyer et al., "A Look into the Amish Culture: What Should We Learn?" *Journal of Transcultural Nursing* 14, no. 2 (2003): 143.

9. A.H.M. Antommaria et al., "Two Infants, Same Prognosis, Different Parental Preferences," *Pediatrics* 135, no. 5 (2015): 918-23; E.A. Gibson, "Caring for a Critically Ill Amish Newborn," *Journal of Transcultural Nursing* 19, no. 4 (2008): 371-4; E. Wright Clayton and E. Kodish, "Baby Aaron and the Elders: A Case Study," *Hastings Center Report* 29, no. 5 (1999): 20-1.

10. M.J. Banks and R.J. Benchot state, "[The Amish] tend to avoid abusive, violent, boisterous or threatening words." "Unique Aspects of Nursing Care for Amish Children," *MCN: The American Journal of Maternal Child Nursing*, 26, no. 4 (2001): 192; Dellasega, Hupcey, and Fisher, "Culturalizing Health Care," see note 4 above, p. 12.

11. See Harry Frankfurt, "Freedom of the Will and the Concept of a Person," in *The Importance of What We Care About: Philosophical Essays* (Cambridge, U.K.: Cambridge University Press, 1988), 11-25.

12. For a description of *gelassenheit*, see D. Kraybill, *The Riddle of Amish Culture* (Baltimore: Johns Hopkins University Press, 1989), 99-100.

13. Concern for respect is a main theme in one study of Plain Anabaptist attitudes regarding healthcare. See Garrett-Wright, Jones, and Main, "Anabaptist Community Members' Perceptions," see note 7 above, pp. 194-5; Weyer et al., "A Look into the Amish Culture," see note 8 above, p. 144.