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At the Intersection of Faith, Culture, and Family Dynamics: A Complex Case of Refusal of Treatment for Childhood Cancer

Amy E. Caruso Brown

ABSTRACT

Refusing treatment for potentially curable childhood cancers engenders much discussion and debate. I present a case in which the competent parents of a young Amish child with acute myeloid leukemia deferred authority for decision making to the child's maternal grandfather, who was vocal in his opposition to treatment. I analyze three related concerns that distinguish this case from other accounts of refused treatment.

First, I place deference to grandparents as decision makers in the context of surrogate decision making more generally.

Second, the maternal grandfather's ardent refusal of treatment and his rationale appeared to be inconsistent with the beliefs expressed by other family members and by members of the same Amish community, leading members of the medical team to question whether refusal of treatment should be treated differently when it appears to be based on the idiosyncratic beliefs of an individual rather than on community-wide values.

Third, the medical team perceived tension and dissension between the nonverbal behavior of some family members and the verbal statements made by the maternal grandfather, leading the team to question the parents' true wishes and debate how to weigh nonverbal and indirect forms of communication.

Finally, building upon the conclusions of these queries, I explore whether, if the child's prognosis was less favorable or if he were to relapse later, the maternal grandfather should have been permitted to drive a decision to refuse further treatment.

CASE PRESENTATION

A three-year-old Amish child presented to the emergency department with a one-week history of fever, rhinorrhea, and decreased appetite, accompanied by his 24-year-old father, his maternal grandfather, and his paternal grandfather. His primary caregiver, his 23-year-old mother, was at home recovering from an illness. On examination, the child was noted to be pale and lethargic, with a profoundly enlarged liver and spleen. Blood tests revealed that his white blood cell count exceeded 100,000 cells/microliter (normal range is five to 15,000); 66 percent were blast (leukemia) cells. He was subsequently admitted for evaluation and treatment of presumed leukemia.

Upon the child's arrival on the inpatient unit, the attending physician discussed the probable diagnosis and necessary additional testing with the father and grandfathers. The initial plan presented to the family included a bone marrow aspirate and biopsy, a diagnostic lumbar puncture with administration of intrathecal chemotherapy, and placement of a tunneled central venous catheter to facilitate

treatment with systemic chemotherapy. The family members were told that specific treatment options and prognosis would be dependent on the type of leukemia identified by the additional testing. The maternal grandfather immediately raised concerns regarding the child's quality of life during therapy, as well as the costs of such treatment, which would be borne by the community, and he expressed doubt regarding whether to treat the child at all. He stated that he wanted to involve other family members and elders from the community. At this point, the physician encouraged the involvement of additional family members and requested that the family meet with an ethics consultant.

The following afternoon, the family provided consent for the procedures after flow cytometric testing confirmed the diagnosis. The patient's father and grandfathers again met with the attending physician, joined by two members of the ethics consultation service. The physician explained that the recommended standard therapy involved four cycles of intensive inpatient chemotherapy and that the child's prognosis would depend on cytogenetic testing, as well as on his response to the first cycle of chemotherapy. Specifically, the family was told that the boy's chance of cure could be as low as 20 percent or as high as 80 percent, and that further information would help determine the prognosis. Prior to the meeting, the medical team had reached a consensus that initial chemotherapy was indisputably in the child's best interests; however, the team also agreed that it was important to fully understand the family's values and beliefs and to obtain their buy-in, if at all possible.

During this meeting, the young father was extremely quiet and spoke only during introductions. Shortly after, the patient was escorted to the pre-operative area, and the grandfathers encouraged the father to accompany his son, while they continued the discussion with the physician and ethics consultants. The maternal grandfather took the lead in explaining his interpretation of his family's faith and culture. From his perspective, he said, it would not be a tragedy if his grandson died in childhood, but instead it would be the will of God, sparing the child from ever falling into sin. The paternal grandfather, who had been silent, became tearful. The maternal grandfather went on to share his perspectives on the freedom of religion, as described in the U.S. Constitution, and his belief that it enshrined the right to refuse treatment for his grandson. Eventually, the stories of several other family and community members who were treated unsuccessfully for cancer emerged from this dialogue.¹ In one relative's case,

the treatment that the family had felt pressured to accept was later described as "futile" by another physician, a statement that both devastated and frustrated her kin.

The maternal grandfather requested a day to consider the information provided and to discuss the situation with his community. In pursuit of the goal of establishing therapeutic rapport, the team agreed to his request. Given the degree of hyperleukocytosis, which placed the child at increasing risk of a fatal stroke or pulmonary edema, they felt that a longer delay was not medically safe for the boy. When the maternal grandfather asked what would happen if they decided to refuse therapy, the attending physician gently explained that she would need to take legal action to protect the child and compel treatment; however, she emphasized that if the patient had features suggesting high-risk or difficult-to-treat disease, they would revisit the possibility of foregoing curative treatment in favor of comfort care only.

The following day, the family consented to chemotherapy and the child began treatment. The family members at the bedside varied, including combinations of his mother, father, and both sets of grandparents. The careproviders noted that the family seemed to follow a strict hierarchy, in which the eldest male relative present in the room would answer and ask all questions. The patient's grandmothers only spoke when no men were present, and the patient's mother only spoke when she was alone with her son and a healthcare provider.

Both the medical team and the family seemed to feel that an acceptable compromise had been reached. The child would receive one cycle of chemotherapy according to the standard of care, but would receive further cycles only if his prognosis proved favorable. Practically, this allowed his care to move forward immediately, yet it left many ethical concerns unresolved. As the first doses of chemotherapy were administered, the maternal grandfather shared that he had prayed for the child to die during the previous night, in order to spare them all the ordeal of treatment.

CASE ANALYSIS

While all involved awaited additional test results, questions arose regarding the medical, ethical, and legal options if the child's prognosis was poor. Some of these were familiar ethical questions regarding the roles of risk and uncertainty in determining thresholds for intervention by the state. Among the members of the pediatric oncology team

and the pediatric residents, an energetic debate took place: What probability of cure was sufficiently high to compel a family to accept treatment for a young child over the objections of family? Responses varied dramatically, with some careproviders arguing that a 20 percent chance of survival was a chance that every child was entitled to have, regardless of a family's personal, religious, or cultural beliefs, while others felt that a 50 percent chance of survival was also a 50 percent chance of a child dying in circumstances that violated a family's deepest values. This is consistent with the lack of a demonstrated consensus in the published literature on refused treatments. I acknowledge these questions, but they are not the primary focus of the analysis, as they have been extensively explored elsewhere.

This case stood apart from other accounts of refused treatment in pediatric oncology because of the particular dilemma that arose from the parents' conscious and consistent deferral of decision-making authority to the maternal grandfather, a practice that diverges considerably from the mainstream American approach to child rearing and decision making for children.

This analysis will explore three related concerns. First, I place deference to grandparents as decision makers in the context of surrogate decision making more generally, asking whether it is permissible for a grandfather to refuse treatment on behalf of his grandchild. Second, the medical team perceived tension and dissension between the nonverbal behavior of some family members and the verbal statements articulated by the maternal grandfather, leading the team to question the parents' true wishes and to debate how to weigh nonverbal and indirect forms of communication. Third, the maternal grandfather's ardent refusal of treatment and his rationale appeared inconsistent with the beliefs expressed by other family members and by members of the same Amish community, which raised questions of whether refusal of treatment should be treated differently when it appears to be based on the idiosyncratic beliefs of an individual, rather than on the values shared by the patient's community. Finally, building on answers to these queries, I conclude with a consideration of whether, if the child's prognosis were unfavorable or if he were to later relapse, the maternal grandfather should be allowed to drive a decision to refuse further treatment.

Parental Deference of Decision-Making Authority to Grandparents

In this case, the decision that treatment was obligatory was rooted in the ambiguity of the child's

prognosis. Unlike other prominent cases that have been subject to scholarly analysis and media attention, the child's prognosis at the time of the diagnosis could not be determined without further information, including his response to initial treatment.² Discussions amongst the team indicated a substantial "gray zone" of disagreement regarding the ethics of legally compelling treatment in the face of an uncertain prognosis. Depending on certain prognostic factors, the child might have had as little as a 20 percent chance of survival, at which point many of the medical team members stated a reluctance to request intervention by the state. When all of the prognostic information was available, four weeks into treatment, the child's likelihood of survival was thought to be closer to 80 percent, a threshold at which most, but not all, of his careproviders felt that treatment was obligatory. Highly personalized and specific prognostic information is an increasingly common feature of pediatric oncology care; therefore, this aspect of the case is likely to be a feature in future conflicts regarding the refusal of treatment.³

Had this patient been shown to have a high-risk disease up front, or were he to relapse in the future, his best chance of cure would rely on a bone marrow transplant, which would entail greater medical expense, geographic separation for the family, and a potential for physical pain, life-threatening complications, and lifelong adverse effects.⁴ If a bone marrow transplant was necessary to achieve a cure, should the family—with their belief that a short, good life was better than a longer one with more suffering, even temporary suffering, and their concerns about expense and geographic separation—be obligated to proceed with such an intervention? Should the maternal grandfather be allowed to drive a decision to forego treatment at that point?

In the United States, parents generally have the legal authority to make medical decisions for their child.⁵ This surrogate decision-making authority is grounded in several assumptions: that (1) parents are likely to know their child best and therefore are best positioned to make decisions in their child's best interests, (2) parents are best positioned to weigh the potentially competing interests of other family members against the interests of their child,⁶ (3) parents are typically the most invested in any potential outcome, and (4) parents should be allowed to raise their child in accordance with their values, beliefs, and customs. This encourages a level of investment in the patient's family that would be forsaken if their autonomy were circumscribed too greatly.⁷

The language of surrogate decision making in Western medicine tends to be highly individualis-

tic.⁸ Standards for making decisions for an incapacitated adult typically presume that a surrogate will act as the patient would have wanted, or, when what the patient would have wanted is unknown, in the patient's best interests.⁹ Among the Amish, the best interests of all children—to be raised within a community that values hard work, interdependence, and self-sufficiency, and that is separate from the corrupting influences of the modern and materialistic world—outweigh the individual interests of one child.¹⁰ From the perspective of the patient's maternal grandfather, this would be true even should the "interests" of the child in question become a matter of life and death.¹¹

Grandparents who do not have legal guardianship of a child do not have any legal rights to make major medical decisions for their grandchildren in the U.S., and they certainly cannot overrule the decision of a parent, except in specific circumstances involving legal guardianship.¹² However, in some families, grandparents may demonstrate all of the qualities that identify parents as optimal surrogate decision makers. Within the context of the Amish community, some grandparents may have a better understanding of the potential impact of extraordinarily costly treatment on their community and a deeper appreciation for the proposed treatment, compared with young parents with limited exposure to the non-Amish world. Grandparents' greater life experience may equip them to better appreciate the benefits and burdens of treatment in the context of community resources, traditions, and faith. Certainly no law prohibits parents from voluntarily consulting or even deferring their decision-making authority to a child's grandparents or another relative.

Exceptions and limitations to parental—and, by extension, *grandparental*—authority vary from state to state in the U.S., but they have typically allowed for adolescent patients to make their own decisions in matters of sexual, reproductive, or mental health and substance abuse, and for the state to intervene when parents' decisions (or lack thereof) would be very likely to cause substantial or irreparable harm to a child's health.¹³ The accepted thresholds for state intervention in the U.S. have varied widely, with little consensus between physicians, hospitals, courts, and states, except at the extremes.¹⁴ For example, in *Newmark v. Williams*, the Supreme Court of Delaware ruled in favor of allowing the parents of a three-year-old boy with Burkitt lymphoma to decline treatment that would have given him a 40 percent chance of survival.¹⁵ This decision was based in part on an exemption for "spiritual treatment" in the state's child abuse and neglect statutes, and in

part on the 60 percent chance that the treatment would cause debilitating side-effects yet fail to effect a cure.¹⁶ While some states have repealed such exemptions or "religious shield" laws, others remain in place.¹⁷

Tension Between Verbal and Nonverbal Communication

In this case, the first indication that statements made by the boy's maternal grandfather might not represent the beliefs of other family members came during a meeting between the family, attending physician, and ethics consultants. The maternal grandfather exuded serene conviction: he was verbally and physically unwavering. Yet when he stated firmly that he did not see early death as tragic, the child's paternal grandfather began to cry silently, leading those present to wonder if he fully shared his kin's views.

As the first cycle of chemotherapy progressed, the pediatric oncologists, residents, nurses, and support staff slowly built rapport with the patient and his family. Many staff observed that neither parent, when encountered alone at the patient's bedside during treatment, ever spontaneously voiced an objection to treatment. In hindsight, no careprovider could recall a conversation with any relative, other than the maternal grandfather, regarding refusal of treatment, although most acknowledged that they did not deliberately raise the subject themselves.

Like most Amish families, this family did not purchase medical insurance or accept governmental assistance. When caring for other families who pay for treatment out of pocket for these reasons, the team was accustomed to articulating the specific rationale for each test and intervention, allowing the family to consider the cost relative to potential benefit. It was therefore surprising that these types of conversations never occurred with this child's parents. Neither his mother nor his father questioned the day-to-day recommendations of the medical team, even when these included additional tests or other interventions to ameliorate adverse effects. Some team members interpreted the absence of this behavior to be further evidence that the parents did not agree with the maternal grandfather.

The team noted that the parents were quick to reach out to and support other families on the pediatric oncology service, suggesting questions to ask and inquiring about the other children's diagnoses and treatment. This active engagement with hospital life seemed to suggest a growing investment in the hospital community, and, by extension, their child's place in it. At home, neighbors helped the

family to contact a naturopathic practitioner in an adjacent state who recommended several vitamin and herbal supplements to manage the potentially adverse effects of therapy.¹⁸ The parents willingly provided the supplements to the oncology pharmacist to research and examine prior to administration. The child's father seemed intrigued by Western biomedicine and even occasionally stood outside the conference room where weekly "grand rounds" were held, listening to the lectures.

The patient had favorable cytogenetic features and an excellent response to the first cycle of chemotherapy, with no minimal residual disease detectable in his bone marrow. Three additional cycles of chemotherapy were therefore administered, in accordance with the initial compromise. The maternal grandfather never attempted to interfere with the administration of care, but he continued to spontaneously raise the subject of refusing further treatment during his visits to his grandson's bedside. He expounded on the personal, religious, and cultural reasons he would have chosen not to treat the child and argued against legal and ethical perspectives that favored treatment. His declamations left little doubt that the initial acquiescence to treatment was primarily motivated by recognition of legal consequences and a desire to avoid the involvement of Child Protective Services.

By the end of therapy, the parents, paternal grandparents, and maternal grandmother had begun to frequently express their gratitude to the staff and their trust in the primary oncologist. However, they never publicly disagreed with the maternal grandfather, and all family members had many private opportunities to speak with the medical team.

Personal, Family, Cultural, and Religious Beliefs: Are All Beliefs Created Equal?

Compelled medical treatment may be experienced by the members of a minority community as a "threat to, or violation of, their chosen way of life by the outside world" that may be transmitted to their children in form of fear, anxiety, and chronic stress; some adults and children may, however, be "relieved to be compelled to do things their religion precludes them from doing voluntarily."¹⁹ The possibility that this child's parents belonged in that latter group contributed greatly to the emotional and moral distress experienced by the medical staff.

The maternal grandfather's beliefs, although articulate and impassioned, did not appear wholly representative of the beliefs of other Amish families treated at the same institution, who were typically willing to accept treatment for childhood cancer,

even in the presence of uncertainty, unfamiliarity, and at times skepticism toward Western medicine, and despite serious concerns about the costs of care.²⁰

With regard to the potential financial burdens on farming communities of limited resources, the perspectives of the staff were mixed. Many of the staff who were involved in this case expressed admiration for the interdependent way of life found in Amish communities and questioned the morality of compelling the community to place one child's needs above the needs of all of the others. Other staff expressed frustration, and argued that this approach was inherently flawed, since the patient would have qualified for Medicaid if the community had chosen to participate in state and federal assistance programs.²¹ The impact of a single child's resource-intensive medical care on the resources available to care for other children was not something that could be reliably assessed. The staff never felt that the boy's family believed that treating him would result in other children going without food, clothing, or shelter, would force other parents in the community to forego seeking medical attention, or would seriously disrupt the integrity of the community by limiting available resources.

Furthermore, while other Amish may share the maternal grandfather's belief that death before the age of sin guarantees salvation, they generally place emphasis on the idea that "those who worship God, obey the church, provide for family and community will enjoy salvation."²² Neither individual and institutional experience nor a review of the literature produced any support for the idea that the death of a child would not be grieved as a loss for an Amish parent.²³

If the boy's family had chosen to forego treatment, and the moral validity of their decision was rooted in respect for the Amish community and the value of protecting that way of life, would the medical team have been obligated to advocate for more involvement from the community? Would that obligation have been greater if it became apparent that the maternal grandfather's interpretation of his religious beliefs was idiosyncratic? The maternal grandfather initially requested that the ethics consultants meet with community elders, but he later changed his mind, and the proposed meeting did not go forward. This was a lost opportunity to directly address the question of whether treating *this* child for cancer was counter to Amish values and would jeopardize the Amish way of life. Theologian Daniel Sulmasy has written persuasively that faith derived from organized religion is, by definition, public (in

the sense of communal) and not private, stating, “judging the authenticity of families’ claims” requires “examining such claims in light of . . . the person’s own religious tradition.”²⁴

It must be noted that no member of this patient’s family ever argued for the merits of spiritual or faith healing or of complementary and alternative therapies alone, another typical feature of previously published accounts of refused treatment in this context. Instead, speaking for everyone involved, the maternal grandfather explained that the members of the community accepted that God’s will would be done, regardless of their decisions and interventions, that they accepted that God’s will might be the patient’s death, and that they would therefore prefer to avoid the perceived harms to both the patient, in terms of side-effects from intensive chemotherapy, and to their community, in terms of shared financial burden.²⁵

In the “Gray Zone”: Who Should Decide What to Do?

The juxtaposition of (1) the maternal grandfather’s observed status as the most senior and respected figure in the family, with (2) the child’s parents’ apparently growing acceptance of Western biomedicine, and (3) and the sense that treatment was *not* incompatible with the Amish way of life, created tension for the treating medical team. Many staff felt intuitively that, in the event of the progression of the child’s disease or relapse, his parents would be inclined to treat the child more aggressively. When asked, however, the patient’s mother always deferred to her husband, who in turn expressed the desire to consult their families—who naturally included the maternal grandfather—before making a major decision. As the maternal grandfather remained the only person whose beliefs were clearly articulated, the staff were aware that he would most likely refuse further treatment, especially treatment that would be more intensive and possibly less effective.²⁶

The family’s nonverbal behavior and indirect statements suggested possible discord between the legal decision makers, the parents, and the *de facto* decision maker, the maternal grandfather. For the medical team, this was an ethical issue with an inevitable affective component. When they contemplated the realistic chance of relapse and the possible outcomes, the idea of allowing a child to die, when his mother might want to give him a chance to live, was devastating. Yet it also could not be assumed that the hierarchy of the family and community had been forced on the parents, when it might

very well be a feature of their culture that they embraced.

Nonverbal communication is not typically given much weight in guidelines regarding informed consent. It is, however, a crucial part of how patients, families, and healthcare providers interact, and often nonverbal behavior is the only indication careproviders receive that consent is truly voluntary and free of coercion. In this case, careful study of nonverbal cues and indirect statements yielded paradoxical outcomes: the parents seemed to both favor treatment of their child and to accept the maternal grandfather’s role in decision making.

DISCUSSION

The apparently positive outcome at the time of this analysis was certainly enhanced by the dedication, patience, and care shown by the staff. This patience may be particularly important to Amish families, who may approach a new physician with a sense of “wariness about providing too much information to someone of the world, no matter how well intentioned.”²⁷ However, it is important to consider what was learned, as it sheds light on what could be done better, both in the event of this patient’s relapse and in similar future cases.²⁸

This situation could have benefitted from more intentional communication about decision-making roles and responsibilities with all of those involved. It was unclear whether the patient’s mother had ever explicitly been *asked* about her desired role in decision making or her preferences regarding her father’s role in decision making for her son. In the crucial first 72 hours after the child was admitted to the hospital, no attempts were made to contact the mother at home, and her lack of involvement was accepted at face value, as a nonnegotiable, practical matter. Equally concerning, the patient’s father was likewise never taken aside to privately confirm his wishes regarding how decisions were to be made. His compliance with his father-in-law’s suggestion that he accompany his son to the operating room during the initial ethics consultation was accepted as proof of his desire to have one or both of the child’s grandfathers acting as his surrogate.

Eliciting with certainty whether the parents, particularly the patient’s mother, had voluntarily granted the maternal grandfather this authority was a perplexing task. In many healthcare situations, a dichotomy is observed between a patient’s verbal statements and his or her behavior: careproviders recognize that a person’s interests and preferences may be conveyed through actions and behaviors.

Over time, the team had many more opportunities to observe the mother's interactions with her son. The ethics of care in this situation seemed to demand special consideration of the mother's obvious love and devotion to her child—particularly as her voice was the least heard.²⁹

Although both grandfathers were present for the initial discussion, the maternal grandfather was much more loquacious and assertive. This may have reflected his seniority, being older than the paternal grandfather, or the esteem with which he was held by his community, but it was likely also a function of his personality and temperament.³⁰ Some of the discomfort felt by team members might have been ameliorated if they had better understood the family's private processes for making decisions. Direct engagement with the community's elders might also have helped to address the concerns of the staff that the maternal grandfather's outspokenness was silencing a mother and father who truly did want to optimize their son's chances for survival.

CONCLUSIONS

This case illustrates the challenges of fully comprehending the complexity of values, beliefs, culture, and interpersonal dynamics when faced with a child who needs urgent treatment. It argues against the expectation of quick resolutions after initial ethics consultations: only over the course of several months was the team able to truly appreciate the scope of opinions within the family and the place of those opinions within the larger Amish community. In all interactions with patients, but especially those for whom the stakes are highest, it is crucial that nonverbal information be assessed and considered alongside the spoken word.

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PRIVACY OF PATIENTS AND THIRD PARTIES

The above case has been stripped of all identifying information of involved parties, and non-essential details have been fictionalized or left vague to further protect privacy interests. Written informed consent was not obtained.

NOTES

1. The maternal grandfather described an experience that justified his mistrust of Western physicians. In the aforementioned case, a young woman in the family collapsed at home and was eventually resuscitated and admitted to an intensive care unit. Despite severe anoxic brain injury sustained during the resuscitation efforts, she was maintained on cardiovascular support medications and mechanical ventilation for several days before the family was told that they should discontinue treatment. According to the maternal grandfather, the physician who finally gave this recommendation told them that the interventions were known to have been futile upon her admission. The grandfather therefore felt that the family had been deliberately misled about the possibility of recovery, and that their beliefs, as well as their financial circumstances, had been knowingly disrespected.

2. L.F. Ross, "Against the Tide: Arguments Against Respecting a Minor's Refusal of Efficacious Life-Saving Treatment," *Cambridge Quarterly of Healthcare Ethics* 18, no. 3 (2009): 302-15; Z. Williams, "When the Physician Says You Have to Get the Shot, but Mommy Says No: The Cases of Taige Mueller and Daniel Hauser, and How the State May Force Parents to Accept Unwanted Medical Treatment for their Children," *Indiana Health Law Review* 8 (2011): 199; D.M. Miller, "Legal Matters: Protecting the Right to Choose CAM Over Conventional Medicine: The Case of Daniel, Colleen, and Anthony Hauser," *Alternative and Complimentary Therapies* 15, no. 5 (2009): 261-6; M. McCoy, "Autonomy, Consent, and Medical Paternalism: Legal Issues in Medical Intervention," *Journal of Alternative and Complementary Medicine* 14, no. 6 (2008): 785-92; D.P. Olsen, "Unwanted Treatment," *American Journal of Nursing* 107, no. 9 (2007): 51-3.

3. C. Bachas et al., "High-Frequency Type I/II Mutational Shifts between Diagnosis and Relapse Are Associated with Outcome in Pediatric AML: Implications for Personalized Medicine," *Blood* 116, no. 15 (2010): 2752-8; L.A. Garraway, J. Verweij, and K.V. Ballman, "Precision Oncology: An Overview," *Journal of Clinical Oncology* 31, no. 15 (2013): 1803-5.

4. G.J.L. Kaspers, "Pediatric Acute Myeloid Leukemia," *Expert Review of Anticancer Therapy* 12, no. 3 (2012): 405-13.

5. L.M. Kopelman, "The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness," *Journal of Medicine and Philosophy* 22, no. 3 (1997): 271-89.

6. E.K. Salter, "Deciding for a Child: A Comprehensive Analysis of the Best Interest Standard," *Theoretical Medicine and Bioethics* 33, no. 3 (2012): 179-98.

7. D. Diekema, "Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention," *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 243-64.

8. A. Ho, "Relational Autonomy or Undue Pressure? Family's Role in Medical Decision Making," *Scandinavian Journal of Caring Sciences* 22, no. 1 (2008): 128-35.

9. J.T. Berger, E.G. DeRenzo, and J. Schwartz, "Surro-

gate Decision Making: Reconciling Ethical Theory and Clinical Practice,” *Annals of Internal Medicine* 149, no. 1 (2008): 48-53.

10. C. Mills, “The Child’s Right to an Open Future?” *Journal of Social Philosophy* 34, no. 4 (2003): 499-509.

11. It is worth noting that most sources cite relatively low rates (5 percent) of departure from the Amish community, in contrast to studies of other religious minority groups such as the Jehovah’s Witnesses, in which two-thirds of children leave the church in adulthood, so it is reasonable to conclude that the patient would eventually grow to share some of all of these values, although perhaps not his grandfather’s more extreme theological views. T.J. Meyers, “The Old Order Amish: To Remain in the Faith or to Leave,” *Mennonite Quarterly Review* 68, no. 3 (1994): 378-95; Pew Forum on Religion and Public Life, “U.S. Religious Landscape Survey: Religious Affiliation: Diverse and Dynamic,” February 2008, <http://www.pewforum.org/files/2013/05/report-religious-landscape-study-full.pdf>.

12. In 2007 in Washington State, a 14-year-old boy refused blood transfusions during treatment for curable cancer on the basis of his religious beliefs as a Jehovah’s Witness. His aunt and legal guardian supported his decision, while his biological parents opposed it. The court upheld his right to refuse, and he died.

See note 2 above; E.B. Brandt, “De Facto Custodians: A Response to the Needs of Informal Kin Caregivers?” *Family Law Quarterly* 38, no. 2 (2004): 291-314.

13. M.A. McCabe, “Involving Children and Adolescents in Medical Decision Making: Developmental and Clinical Considerations,” *Journal of Pediatric Psychology* 21, no. 4 (1996): 505-16.

14. J.D. Hord et al., “Do Parents Have the Right to Refuse Standard Treatment for their Child with Favorable-Prognosis Cancer? Ethical and Legal Concerns,” *Journal of Clinical Oncology* 24, no. 34 (2006): 5454-6.

15. *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991).

16. *Ibid.*

17. H. Hall, “Faith Healing: Religious Freedom vs. Child Protection,” *Skeptical Inquirer* 38, no. 4 (July-August 2014), http://www.csicop.org/si/show/faith_healing_religious_freedom_vs_child_protection.

18. This surprised the medical staff; however, the use of complementary and alternative medicines, including vitamins and other supplements labeled “natural,” has been reported elsewhere to be common among the Amish. S.M. Weyer et al., “A Look Into the Amish Culture: What Should We Learn?” *Journal of Transcultural Nursing* 14, no. 2 (2003): 139-45.

19. J.G. Dwyer, “Spiritual Treatment Exemptions to Child Medical Neglect Laws: What We Outsiders Should Think,” *Notre Dame Law Review* 76, no. 147 (2000): 147-77.

20. J.F. Henderson and R.D. Anbar, “Care for Amish and Mennonite Children with Cystic Fibrosis: A Case Series,” *BMC Pediatrics* 9, no. 1 (2009): 1.

21. C.E. Adams and M.B. Leverland, “The Effects of Religious Beliefs on the Health Care Practices of the Amish,” *Nurse Practitioner* 11, no. 3 (1986): 58-63.

22. D.J. O’Neil, “Explaining the Amish,” *International Journal of Social Economics* 24, no. 10 (1997): 1132-9.

23. This discrepancy underlines the importance of avoiding assumptions based on previous experience with families from the same culture or on readings and popular media coverage about the culture, since individuals from the same religious or ethnic background often do have unique interpretations of their culture and beliefs. L. Wiener, D.G. McConnell, L. Latella, and E. Ludi, “Cultural and Religious Considerations in Pediatric Palliative Care,” *Palliative and Supportive Care* 11, no. 1 (2013): 47-67.

24. D.P. Sulmasy, “Distinguishing Denial from Authentic Faith in Miracles: A Clinical-Pastoral Approach,” *Southern Medical Journal* 100, no. 12 (2007): 1268-72.

25. See note 2 above.

26. Kaspers, “Pediatric Acute Myeloid Leukemia,” see note 4 above.

27. L.L. Graham and J.A. Cates, “Health Care and Sequestered Cultures: A Perspective from the Old Order Amish,” *Journal of Multicultural Nursing & Health* 12, no. 3 (2006): 60.

28. Kaspers, “Pediatric Acute Myeloid Leukemia,” see note 4 above.

29. R. Tong, “The Ethics of Care: A Feminist Virtue Ethics of Care for Healthcare Practitioners,” *Journal of Medicine and Philosophy* 23, no. 2 (1998): 131-52.

30. Graham and Cates, “Health Care and Sequestered Cultures,” see note 27 above.

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

James L. Benedict

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 con-

flict. 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

James L. Benedict, PhD, is a Scholar in Residence at the Center for Healthcare Ethics at Duquesne University in Pittsburgh, Pennsylvania. benedictj@duq.edu

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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 co-exist 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 disrespected¹³ 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. Gates, *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.