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From the Editors

Nneka Sederstrom and Michael Sprehe

ABSTRACT

The Co-Editors-in-Chief of the *Journal of Pediatric Ethics* welcome the reader to the first issue of the new journal.

Dear Reader,

Thank you for subscribing to the *Journal of Pediatric Ethics*! At Children's Minnesota, we realize, along with many of you, that the ethical issues arising in children and young adults are unique and deserve their own forum. In an effort to address this unmet need, we are establishing this journal to focus specifically on the ethical complexities that arise in pediatric medicine.

As an initial approach, each issue of the journal will be theme based. For our inaugural issue, we chose the topic of bias, given the growing recognition of the impact of bias on healthcare outcomes and health disparities. For subsequent issues in 2017, we will be soliciting articles on communication and on advanced care planning/limitations of treatment.

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The *Journal of Pediatric Ethics* is also interested to hear from families enmeshed in these complex ethical cases. The Family Voice section will be dedicated to parents and families who have experienced situations related to each theme. Our hope is to provide a voice for all parts of a care team, not simply from the healthcare providers.

We are excited to bring you the first ethics journal specific to pediatrics. Our goal is to provide a resource that is useful to all who work with infants, children, and young adults across the spectrum of healthcare, research, and policy. We realize, however, that this is a daunting task with many challenges, and we view this endeavor as a work in progress.

We are looking to you, the reader, to guide us, through your provision of ideas, constructive feedback, and original research during the growing stages of this journal. We will be accepting and publishing letters to the editor in response to articles published, feedback on content, or recommendations for future issues, when appropriate. Together we hope that we can establish a journal that is worthy of the population for which we so passionately care.

Thank you again for your subscription to the journal and welcome to the first ever *Journal of Pediatric Ethics*.

Sincerely,
The Members of the Editorial Board

Features

Gatekeeping and Bias Against Pediatric Risk in Solid Organ Transplant

Aaron G. Wightman and Simon P. Horslen

ABSTRACT

We present the case of a three-year-old boy with an inherited progressive liver disease who developed liver failure and required a liver transplant to survive into adulthood. The child had a second medical condition that increased his risk of poor outcome during a liver transplantation, but the absolute risk was unknowable. Newer regulations, including the 2007 Centers of Medicare & Medicaid Services (CMS), which published the Conditions of Participation (CoPs) for United States transplant centers, fostered a new environment that created incentives for transplant centers to be more conservative in the selection of candidates and altered the traditional role of gatekeeping performed by the transplant team.¹ After reviewing the relevant U.S. transplant policies and their impact on transplant centers, this review seeks to provide ethical arguments related to justice, fairness, and utility in the distribution of scarce organs in this more risk-averse environment. The net effect of the changes in transplant regulation appears to be exclusion of poten-

tial candidates for whom solid organ transplant is clearly in their best interests. The change in the nature of gatekeeping may also undermine the trust of both patients and the public in transplantation.

CASE REPORT

Alan is a three-year-old boy with liver failure due to an inherited progressive liver disease. He has had numerous complications as his liver function worsened, including portal hypertension, coagulopathy, and pathologic fractures. Without a transplant, he is expected to die in 18 to 24 months. Thus, the recommended therapy for his liver failure is transplantation. Liver transplantation is a highly efficacious, life-sustaining therapy. Complicating matters, Alan has a deformity of his cerebral vasculature (Moyamoya disease) that, despite a “successful” revascularization procedure, placed him at increased risk for stroke, particularly in the peri-operative period. After an extensive evaluation, it was determined that the increased risk of peri-operative stroke could not be quantified.

After a discussion with Alan’s hepatologist, Alan’s parents ask that he be considered for transplantation. Alan has an older sibling with the same hepatic disease who is a liver transplant recipient. In discussion, various members of the medical team question whether Alan should be a candidate for transplant because he has an increased risk for poor

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surgical outcome; the transplant may be an inappropriate use of a donor liver; and a series of poor outcomes could affect the center's outcome statistics and potentially result in an audit, negative publicity, loss of inclusion in insurance networks, or closure of the center.

DISCUSSION

The shortage of available organs has been a central concern throughout the history of transplantation. In 2012 there were 585 children on the U.S. pediatric liver transplant wait list and 37 deaths.² In part due to the shortage of organs, transplant physicians have played the role of gatekeeper, choosing only certain individuals to give or receive an organ. In their classic text, Fox and Swazey described the goal of gatekeeping as "to optimize the patient's chances for survival and to offer him as enduring, active, and meaningful a post-transplant life as possible without undue physical, psychic, or social harm to himself, the donor, or their families."³ This patient-centered approach focuses on identifying the medical suitability of a candidate and assessing whether the potential recipient would benefit sufficiently, relative to the burdens transplant would pose to the individual. If there is the potential for sufficient benefit, the patient will be accepted by the transplant center either for a living donor transplant or be placed in a national pool for a deceased donor transplant, for which allocation is based upon explicit criteria.

Liver transplantation represents the single, best, and only definitive therapy associated with prolongation of life in the setting of end-stage liver disease.⁴ A successful transplant in a child of this age could be expected to last for 20 to 30 years.⁵ Liver transplant does carry a risk of death from either the complications of surgery or failure of the allograft. While the risks of peri-operative death or catastrophic neurologic event are higher for Alan than they would be for a similar child experiencing liver failure but who has normal cerebral vasculature, the absolute risk is unknowable. In situations that offer a potential benefit to a child, but also the risk of significant morbidity, a medical team will often defer to the child's parents, recognizing the traditional role of parental authority in medical decision making. In this case, the medical team weighs the risks for Alan, with the added knowledge that he has a sibling who has had liver transplantation. The parents ask the team to proceed with transplant. In their view, the risks of the procedure are justified by its potential benefits.

While different physicians and parents could make different assessments about the candidate's best interests or whether pursuing liver transplantation in this patient represents an effective use of the limited community resource of donated livers, traditionally consideration of a candidate focuses only upon on these largely patient-centered concerns. The 2007 CMS CoPs changed the focus of gatekeeping by introducing a new concern: the viability of the transplant center.⁶ The net effect has been to promote the selection of lower risk candidates and the exclusion of candidates for whom transplant is in their best interests, but who may pose a risk to the viability of the transplant center.

The goal of the CoPs was to create greater transparency for transplant center outcomes and to encourage quality improvement measures.⁷ The CoPs include a set of regulations about minimum patient and graft survival rate criteria that are based upon observed and expected one-year patient and graft survival from reports by the Scientific Registry of Transplant Recipients (SRTR).⁸ These outcomes are evaluated in six-month increments over the previous two and one-half years. Transplant centers that have two periods of performance that are below expected outcomes in the previous two years are required to undergo an audit, at considerable expense, and risk shutdown or exclusion from insurer networks. Smaller transplant centers that perform less than 10 transplants per two and one-half year period, including most pediatric transplant centers, are audited for a single death or graft loss in the first year following transplant. Up to 10 percent of kidney, liver, and heart transplant programs were identified as underperforming by CMS when it examined SRTR program-specific reports for the period 1 January 2005 through 30 June 2007. Some transplant centers reported quality improvements as a result of this auditing.

There are a number of concerns with the CoPs model.⁹ The CoPs model uses a one-sided t-test, rather than the two-sided t-test used by SRTR, to compare observed versus expected outcomes. (A t-test assesses whether the means of two groups are statistically different from each other; a two-sided t-test tests the difference between the samples.) This difference increases the number of transplant centers that may be flagged as poorly performing. The predictive models for expected outcomes are also limited by a low C-statistic. (A C-statistic, or concordance statistic, is a measure of "goodness of fit" for binary outcomes in a logistic regression model.) A low C-statistic is 0.66 for kidneys; 0.5 indicates no predictive value and 1 represents perfect predic-

tive value. Finally, the difference between audited programs and those not audited is not dramatic; Schold and colleagues noted that from 2007 to 2009, the mean difference in one-year graft survival between audited and non-audited transplant centers was less than 5 percent (87.8 percent versus 92.3 percent).¹⁰ Some of these issues have been addressed by a transition from an observed versus an expected analysis to a Bayesian analysis in January, 2015; however, concerns still exist regarding the limitations of the predictive models upon which they are

received one or more offers of a high-quality liver donation. Further, a 2009 survey of transplant providers found that more than half of the transplant centers were less likely to accept medically or socially complex recipients and poorer quality organs.¹³ Among centers that had been audited, more than 80 percent reported more conservative behavior.

A more conservative approach by transplant centers may account in part for the observed decline in the number of pediatric liver and deceased donor

The new regulations have changed the nature of gatekeeping by providing incentives to consider only the lowest risk candidates. As a result, transplant providers' decision making is no longer exclusively patient-centered, but now is focused on the viability of the transplant center.

based. When a model cannot adequately adjust for the medical complexity of a donor recipient and a donor, and the consequences of an audit are potentially severe, it is prudent for a transplant center to become more conservative in the selection of both the recipient of an organ and the selection of an organ. This is the approach taken by the Johns Hopkins adult liver transplant center as part of their Systems Improvement Agreement in 2010.¹¹ As a result of the audit, the transplant center lost several insurance contracts.

We found further evidence of this conservative approach in an anonymous internet survey of 21 surgical and medical directors of pediatric kidney transplantation centers.¹² Respondents were given a variety of vignettes of higher risk including risk of recurrence, patients' noncompliance, multiple medical comorbidities, and shortened life span. In each of these vignettes, careproviders felt that transplantation was in the child's and her family's best interests, however, more than 50 percent of respondents for each case reported they would explicitly consider the potential negative impact of a poor outcome on their center's viability when considering each patient. Similarly, concerns regarding a transplant center's performance may explain the lower than expected acceptance rate for liver grafts observed from 2005 through 2010, and the finding that 55 percent of the candidates for liver transplant who died or who were removed from the transplant list

pediatric kidney transplants performed in the U.S. since the institution of the regulations.¹⁴ The change in careproviders' behavior means that the metric, in effect, is now reflecting the relative complexity of transplant candidates and quality of accepted donor organs at centers, rather than acting as a true marker of the quality of the transplant centers. The net result is that fewer transplants are performed, potentially more donor organs are wasted, and higher risk patients who could benefit from solid organ transplantation are excluded.

The new regulations have changed the nature of gatekeeping by providing incentives to consider only the lowest risk candidates. As a result, transplant providers' decision making is no longer exclusively patient-centered, but now is focused on the viability of the transplant center. This departure from a patient-centered approach has potential consequences, including the introduction of bias against potential candidates on the basis of medical complexity, particularly if a transplant center had a poor outcome with a different patient. The net effect is exclusion of potential candidates for whom solid organ transplant is clearly in their best interests. The change in the nature of gatekeeping may also undermine the trust of patients and the general public in transplantation. In light of these changes, it is important for pediatric transplant decisions to be made carefully, responsibly, and openly, using the best information available, and for parents to be

given the opportunity to appeal decisions and to be informed of the potential to be considered by a different transplant center. Continued progress is needed at the national level in the U.S. to identify new ways to assess quality in an increasingly risk-averse environment.

While it may not be prudent, in the current regulatory climate, we feel the focus of decision making should remain on likelihood of benefit to the child. It would be inappropriate to accept any patient for transplantation if the odds of the survival of the graft or the patient were extremely low, not because of issues of stewardship or the viability of transplant centers, but because it would not be in the patient's interest. Such a patient would be forced to undergo painful surgery for little or no benefit that may, instead hasten death. In situations of uncertainty, such as this case, in which a successful transplant would be of significant benefit to a child but carries a higher risk of peri-operative complications, we should allow the child's parents to choose to pursue potentially efficacious therapy, provided they are adequately informed.

PRIVACY

The case presented above was created as a fictionalized adaptation from several actual cases in pediatric liver, heart, and kidney transplantation that involved similar themes.

NOTES

1. The CMS Conditions of Participation (CoPs) for transplant centers are published in U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, "42 CFR Parts 405, 482, 488, and 498, Medicare Program; Hospital Conditions of Participation: Requirements for Approval and Re-Approval of Transplant Centers To Perform Organ Transplants; Final Rule," 30 March 2007, <https://www.cms.gov/Medicare/Provider-Enrollment-andCertification/GuidanceforLawsAndRegulations/Downloads/TransplantFinalLawandReg.pdf>.

2. Recipients, Scientific Registry of Transplant, "2012 Annual Data Report," http://srtr.transplant.hrsa.gov/annual_reports/20102/Default.aspx.

3. R.C. Fox and J.P. Swazey, *The Courage to Fail: A Social View of Organ Transplants and Dialysis* (Chicago: University of Chicago Press, 1974).

4. D.C. Cronin et al., "Parental Refusal of a Liver Transplant for a Child with Biliary Atresia," *Pediatrics* 131, no. 1 (January 2013): 1414-6.

5. *Ibid.*

6. CMS Conditions of Participation (CoPs), see note 1 above.

7. *Ibid.*

8. M.M. Abecassis et al., "American Society of Trans-

plant Surgeons Transplant Center Outcomes Requirements—A Threat to Innovation," *American Journal of Transplantation* 9, no. 6 (June 2009): 1279-86.

9. *Ibid.*; A.M. Cameron and B.E. Sullivan, "Regulatory Oversight in Transplantation: There and Back Again," *JAMA Surgery* 148, no. 11 (November 2013): 997-8; J.D. Schold, C.J. Arrington, and G. Levine, "Significant Alteration in Reported Clinical Practice Associated with Increased Oversight of Organ Transplant Center Performance," *Progress in Transplantation* 20, no. 3 (September 2010): 278-87; J.D. Schold et al., "The Association of Center Performance Evaluations and Kidney Transplant Volume in the United States," *American Journal of Transplantation* 13, no. 1 (January 2013): 67-75.

10. Schold et al., "The Association of Center Performance Evaluations," see note 9 above.

11. Cameron and Sullivan, "Regulatory Oversight in Transplantation," see note 9 above.

12. A. Wightman, unpublished data; please contact the author for additional information.

13. Schold, Arrington, and Levine, "Significant Alteration in Reported Clinical Practice," see note 9 above.

Cultural Bias in American Medicine: The Case of Infant Male Circumcision

Brian D. Earp and David M. Shaw

ABSTRACT

In 2012 the American Academy of Pediatrics (AAP) released a policy statement and technical report stating that the health benefits of newborn male circumcision outweigh the risks. In response, a group of mostly European doctors suggested that this conclusion may have been due to cultural bias among the AAP Task Force on Circumcision, in part because the AAP's conclusion differed from that of international peer organizations despite relying on a similar evidence base. In this article, we evaluate the charge of cultural bias as well as the response to it by the AAP Task Force, focusing on possible sources of subjective judgments that could play into assessments of benefit versus risk. Along the way, we discuss ongoing disagreements about the ethical status of non-therapeutic infant male circumcision and draw some more general lessons about the problem of cultural bias in medicine.

INTRODUCTION

In 2012 the American Academy of Pediatrics (AAP) released a policy statement and technical re-

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port in which it concluded that the “health benefits of newborn male circumcision outweigh the risks.”¹ In contrast to most policies issued by the AAP, this one proved controversial, not only in the United States but internationally. Part of the reason for the controversy was that its primary conclusion concerning benefits and risks differed from that of previous AAP task forces: while previous task forces had acknowledged both positive and negative aspects to newborn circumcision (with earlier policies recommending against the procedure and later policies adopting a more neutral stance), none had found that the negatives were outweighed by the positives.² More striking, however, was the fact that this same conclusion differed from that of all contemporary peer organizations—that is, national pediatric or general medical societies in other countries with comparable public health environments—despite relying on a similar evidence base.³ Following the release of the AAP documents, international critics raised concerns regarding how the main conclusion had been reached (see table 1).⁴

The most prominent criticism came in the form of an article entitled “Cultural Bias in the AAP’s 2012 Technical Report and Policy Statement on Male Circumcision,” authored by a large group of pediatric and other health authorities from mainland Europe, the United Kingdom, and Canada. According to these authors, “only 1 of the arguments put forward by the [AAP] has some theoretical relevance in relation to infant male circumcision; namely, the pos-

sible protection against urinary tract infections in infant boys, which can easily be treated with antibiotics without tissue loss.”⁵ According to this view, since approximately 100 circumcisions would be needed to prevent one urinary tract infection (UTI),⁶ and since the same theoretical UTI could be treated nonsurgically—as it would be if the child were female—without significantly increasing the absolute risk of serious adverse consequences, most boys with a normally developing anatomy should expect to receive no net medical benefit from circumcision prior to their sexual debut.

The other claimed health benefits, according to the critics, including a reduced risk of female-to-

male heterosexually transmitted human immunodeficiency virus (HIV) and penile cancer, “are questionable, weak, and likely to have little public health relevance in a Western context, and they do not represent compelling reasons for surgery before boys are old enough to decide for themselves.”⁷

Assessing Benefit and Risk

Let us first assess the empirical disagreement concerning benefits and risks. Bostrom and Ord have proposed a “reversal test” for weighing alternative policy options that is useful for framing such an analysis.⁸ Consider the following question: If the AAP had recommended *not* performing circumci-

TABLE 1. Key Reasons for International Skepticism Regarding the 2012 AAP Findings

1. Internal inconsistency	The AAP technical report states that “the true incidence of complications after newborn circumcision is unknown”—due to such problems as inadequate follow-up and conflicting diagnostic criteria—but nevertheless states that the benefits of the surgery outweigh these unknown risks. ¹
2. Questionable methodology	The report does not mention any formal procedure used to assign weights or values to individual benefits and risks, nor does it mention any heuristic by which these could be directly and meaningfully compared, suggesting that no such procedure was used. The AAP Task Force stated in a later publication, the “benefits were felt to outweigh the risks.” ²
3. Underestimation of adverse consequences	The AAP Task Force did not consider the most serious complications associated with circumcision, typically documented in case reports or case series, as these were excluded from their literature review. ³
4. Inadequate description of penile anatomy	The AAP Task Force did not describe the anatomy or functions of the foreskin (the part of the penis removed by circumcision), suggesting that it did not consider this genital structure to have any inherent value. If the foreskin does have value, however, its removal is itself a harm, and this must be factored into any benefit-risk analysis. ⁴
5. Inappropriate use of research findings	The AAP Task Force conflated findings from studies assessing the effects of adult circumcision in sub-Saharan Africa (regarding, e.g., HIV transmission and sexual function) with findings pertaining to newborn circumcision in the U.S., without demonstrating that the two procedures or environments are appropriately analogous. ⁵

NOTES

1. AAP, “Male Circumcision (Technical Report),” *Pediatrics* 130, no. 3 (2012): e756-85, e757.

2. AAP, “The AAP Task Force on Neonatal Circumcision: A Call for Respectful Dialogue,” *Journal of Medical Ethics* 39, no. 7 (2013): 442-43, 442.

3. See, e.g., J.S. Svoboda and R.S. Van Howe, “Out of Step: Fatal Flaws in the Latest AAP Policy Report on Neonatal Circumcision,” *Journal of Medical Ethics* 39, no. 7 (2013): 434-4.

4. The implicit perspective of the AAP Task Force appears to be inconsistent with the value typically assigned to the foreskin in societies where most men retain one (and thus have personal experience with the relevant tissue). The foreskin is a highly touch-sensitive, functional sleeve of tissue that can be manipulated during sex and foreplay: it is therefore *prima facie* reasonable to regard it as having value. For extensive discussion, see B.D. Earp and R. Darby, “Circumcision, Sexual Experience, and Harm,” *University of Pennsylvania Journal of International Law* 37, no. 2 (online 2017): 1-56. The apparent view of the AAP Task Force is also inconsistent with normative medical evaluations regarding other nondiseased body parts: see J.M. Hutson, “Circumcision: A Surgeon’s Perspective,” *Journal of Medical Ethics* 30, no. 3 (2004): 238-40. Consider the female genital labia, for instance, whose functional, sensory, and other attributes would be fully described in any comparable report discussing the merits and demerits of excising them: see e.g., M.P. Goodman, “Female Genital Cosmetic and Plastic Surgery: A Review,” *Journal of Sexual Medicine* 8, no. 6 (2011): 1813-25.

5. M. Frisch et al., “Cultural Bias in the AAP’s 2012 Technical Report and Policy Statement on Male Circumcision,” *Pediatrics* 131, no. 4 (2013): 796-800, 796.; J.A. Bossio, C.F. Pukall, and S. Steele, “Review of the Current State of the Male Circumcision Literature,” *Journal of Sexual Medicine* 11, no. 12 (2014): 2847-64.

sion (because its primary health benefit in childhood could be achieved less invasively and in a more targeted manner via treatment with antibiotics, as noted by the critics), would any significant medical harm result to children, on balance, if all physicians followed that advice?

The most likely answer is “no.”⁹ A recent analysis of 18 years of data from the capital region of Denmark, where nonreligious male circumcision is rarely performed except out of medical necessity, suggests that approximately 99.5 percent of boys will go through infancy, childhood, and adolescence without requiring a circumcision for therapeutic reasons.¹⁰ To put this finding a different way, the data suggest that less than 1 percent of boys in settings comparable to that of the Danish study will face a foreskin-related medical problem requiring circumcision before an age of consent.

By contrast, what would happen if the AAP guidelines were followed? Although the AAP documents do not explicitly recommend newborn circumcision, the “affirmative” position regarding net benefit has been interpreted by some circumcision advocates as entailing a similar conclusion, such that it “should logically result in an increase in infant circumcisions in the United States.”¹¹ If this does occur, the consequence would be that an indeterminate number of boys will have undergone a medically unnecessary genital surgery, the risks of which have not been adequately studied.

For example, with respect to surgical complications, the AAP Task Force states that, due to disagreements about diagnostic criteria and other limitations with the available data, the “true incidence” of surgical complications is currently unknown.¹² Other risks, including psychosexual risks,¹³ risks to the developing nervous system, and long-term risks to neuroendocrine and immune system stress responses¹⁴ are even less well studied. Finally, some risks, including feelings of loss or resentment, dissatisfaction with one’s penile appearance, body-image problems, *et cetera*, are largely subjective in nature. This inherent subjectivity renders these risks difficult if not impossible to measure using standard scientific modalities.¹⁵ Predicting such outcomes across a range of individual difference variables poses an even greater empirical challenge.¹⁶

The Importance of Subjective Factors

Whether boys and men regard themselves as having been harmed versus benefited by nontherapeutic circumcision depends on numerous factors. Among them are differences in attitudes concerning, for example, what constitutes a personally rel-

evant benefit or risk when it comes to a medically elective surgery.¹⁷ Recognizing such variability, a member of the AAP Task Force later acknowledged certain difficulties with the methodology employed by the task force in carrying out its risk-benefit assessment. Specifically, there was a “lack of a universally accepted metric to accurately measure or balance the risks and benefits [as well as] insufficient information about the actual incidence and burden of non-acute complications.”¹⁸

Why is there no “universally accepted metric” for balancing risks and benefits? One reason is that any such metric is likely to be influenced, whether consciously or unconsciously, by the beliefs, values, and personal preferences of those applying it to the evidence.¹⁹ As Akim McMath notes, “People disagree over what constitutes a harm and what constitutes a benefit” when it comes to circumcision.²⁰ For example, “some people believe circumcision benefits the child by bringing him closer to God, while others disagree” (see box 1).²¹

Such divergent prior beliefs, in turn, may influence how one interprets the relevant medical evidence. Consider a person who is committed to circumcising infants on religious grounds. Perhaps believing, on first principles, that God would not endorse a practice that was physically harmful, it is possible that such a person would be less inclined to regard the risks that have been attributed to circumcision as being empirically well supported. This inclination, in turn, could lead a person to give relatively more credence to evidence that appears to suggest a benefit-to-risk ratio in favor of circumcision, at least partially independently of the actual strength of the evidence.²²

Now consider someone who regards nontherapeutic genital surgery performed on children as immoral, perhaps believing that such surgery violates a child’s right to bodily integrity. Compared to a religious supporter of circumcision, this person might evaluate the same evidence rather differently. Since a finding of net medical or other harm would be *prima facie* more congenial to their moral stance, this person might give relatively more credence to evidence that appears to suggest a benefit-to-risk ratio weighing against circumcision, again at least partially independently of the actual strength of the evidence.

Even when there is widespread agreement about what constitutes a harm or benefit, the *weight* to be assigned to the outcome may still differ from person to person. Relevant factors in assigning such weight include one’s tolerance for certain types of risk compared to others (for example, risks of omis-

sion versus commission, risks affecting some parts of the body versus others); the availability of alternative risk-reduction or benefit-promoting strategies and how one ranks these compared to the surgical option; and one's preferences and values regarding bodily aesthetics, sexual behavior, and the importance of conforming or not conforming to prevailing sociocultural norms.

To illustrate, some men might be less comfortable taking on the risks of circumcision, an act of commission (for example, glans amputation or loss of sexual function), than they are taking on the risks of failing to undergo circumcision, an act of omis-

sion (for example, acquiring a treatable infection or developing a rare form of cancer in old age). For many people, the risks associated with acts of commission, versus acts of omission, loom larger in the mind, creating a greater psychological burden and potential for regret. This asymmetry may obtain even when the absolute likelihood of an "omitted" risk is greater than that of a "committed" risk. Without knowing which type of risk a person is more comfortable taking on, however, it is not possible to determine which one "outweighs" the other.

For another example, consider that some men assign a positive value to the foreskin itself, to sexual

BOX 1. Disagreement about Benefits and Risks: What Are the Ethical Implications?

Faced with the problem of disagreement over what constitutes a benefit or risk when it comes to circumcision, it is often concluded that "the parents should decide." However, this does not necessarily follow. As McMath notes, "the child will have an interest in living according to his own values, which may not reflect those of his parents . . . Only the child himself, when he is older, can be certain of his values." Thus, "if disagreement over values constitutes a reason to let the parents decide, it constitutes an even stronger reason to postpone the decision until the child himself can decide."¹

Against this view, it is sometimes argued that infant circumcision is less risky than adult circumcision, such that the two are not equivalent choices. It is true that the two choices are not identical. However, at least two issues need to be clarified before the ethical implications of this fact can be assessed. First, the claim of "less risk" is not uncontroversial. It is based largely upon retrospective comparisons of nonconcurrent studies with results drawn from dissimilar populations, using dissimilar methods and criteria for identifying complications. Therefore, such comparisons do not adequately control for the skill of the practitioner, the specific technique employed, the setting of the surgery, the methods of data collection, and so on.²

Second, even if one were to grant an increase in the *relative* risk of complications in adulthood versus infancy, it is the difference in *absolute* risk that is more ethically relevant. Even strong proponents of infant circumcision contend that the absolute likelihood of clinically important, difficult-to-resolve surgical complications associated with circumcision is "low," regardless of the age at which the procedure is performed.³ Given such a low baseline risk, according to the proponents, the existence of a relative risk reduction in the incidence of adverse events in infancy compared to adulthood is unlikely to be morally decisive. Instead, as the U.S. Centers for Disease Control and Prevention (CDC) states, "Delaying male circumcision until adolescence or adulthood obviates concerns about violation of autonomy" such that any medical disadvantages associated with such a delay "would be ethically compensated to some extent by the respect for the [bodily] integrity and autonomy of the individual."⁴

NOTES

Materials in this box are adapted from B.D. Earp, "Male Circumcision: Who Should Decide?" *Pediatrics* 37, no. 5 (2016): e-letter; B.D. Earp, "Do the Benefits of Male Circumcision Outweigh the Risks? A Critique of the Proposed CDC Guidelines," *Frontiers in Pediatrics* 3, no. 18 (2015): 1-6.; B.D. Earp and R. Darby, "Circumcision, Sexual Experience, and Harm," *University of Pennsylvania Journal of International Law* 37, no. 2 (online 2017): 1-56.

1. A. McMath, "Infant Male Circumcision and the Autonomy of the Child: Two Ethical Questions," *Journal of Medical Ethics* 41, no. 8 (2015): 687-90, 689.

2. H.A. Weiss et al., "Complications of Circumcision in Male Neonates, Infants and Children: A Systematic Review," *BMC Urology* 10, no. 2 (2010): 1-13; J.S. Svoboda and R.S. Van Howe, "Circumcision: A Bioethical Challenge," *Journal of Medical Ethics* 40, no. 7 (2013): e-letter.

3. B.J. Morris and E.C. Green, "Circumcision, Male," *Blackwell Encyclopedia of Health, Illness, Behavior, and Society* (Hoboken, N.J.: Wiley-Blackwell, 2014).

4. U.S. Centers for Disease Control and Prevention, "Background, Methods, and Synthesis of Scientific Information Used to Inform the Draft Recommendations for Providers Counseling Male Patients and Parents Regarding Elective Male Circumcision and the Prevention of HIV Infection and Other Adverse Health Outcomes," *U.S. Centers for Disease Control* (2014): 1-61, 39-40.

activities that require manipulation of the foreskin, or to the embodied state of genital intactness (that is, having a surgically unmodified penis).²³ Compared to men who assign a neutral or negative value to the foreskin, perhaps due to differing beliefs or cultural norms, the former are at a far greater risk of losing a good to circumcision: nearly 100 percent for the above-mentioned factors.²⁴ The magnitude or importance of that risk, in turn, depends on how much value a man places on such factors, which is not something that can be known before he is mentally mature.

Consider, for instance, a recent study of 196 sexually active Canadian adults that found that men who have sex with men (MSM), compared to het-

erosexual females, “indicated a strong preference toward intact penises for all sexual activities assessed and held more positive beliefs about intact penises.”²⁵ This finding suggests that parents who authorize an elective circumcision for their infant son may risk differentially affecting his future sexual enjoyment depending upon his sexual orientation—something that will not be apparent until years later (see box 2 for further discussion).

To summarize, assessments of the comparative worth or weight of particular benefits and risks come down in large part to what one values or prefers. In asserting that the benefits of circumcision outweigh the risks, therefore, the AAP Task Force appears to have substituted its own subjective preferences and

BOX 2. Dealing with Uncertainty About Infants' Future (Bodily) Preferences

Not knowing a child's future preferences poses a challenge to parental and clinical decision making with respect to a wide range of potential pediatric interventions. When it comes to surgeries that permanently alter the body (for example, by removing nonregenerating tissue), it is sometimes pointed out that, whatever choice they make, parents will foreclose at least one future option for their child. Specifically: “parents who decide in favor of early surgery close off the child's future ability to make his own decision regarding surgery . . . while parents who refrain from early surgery close off the option for the [child] to undergo the surgery *during infancy or early childhood*.”¹

Are these cases symmetrical? Circumcision provides a good illustration. If a noncircumcised adult is considering circumcision, for whatever reason, he can perform his own risk-benefit analysis of the surgery, taking into account his known preferences and the fullness of his social, sexual, and other circumstances. If he then chooses circumcision, he will be secure in the knowledge that he has done so voluntarily, undertaking a certain amount of risk to achieve a desired outcome. In other words, the adult with unmodified genitals—who now prefers that they be altered—has an option available with which to satisfy the preference, even if it is not ideal from his current perspective. By contrast, the man whose early circumcision was not desired, and is now a cause of significant distress, has no comparable remedy. He may attempt artificial foreskin “restoration”—if he has enough remaining penile skin to do so—but this may take years to accomplish, and the result will be a mere approximation of a prepuce, lacking the original tissue and nerve endings. Thus, it appears that the two cases are not symmetrical. In the deferred surgery case, there is far greater leeway for the individual to rectify an undesired situation.

Now, it could be argued that the noncircumcised man who wishes he were circumcised cannot truly satisfy his preference either. He may wish, for example, that the surgery had already taken place, perhaps in infancy, so that he would not now have to face the inconvenience. In this respect, he is not unlike the adult female in a similar social context who decides to undergo elective labial surgery for what she considers to be cosmetic reasons. Perhaps it would have been better—from her current perspective—to have undergone the procedure shortly after birth, so that she likewise would not have to face it now. But very few people in Western medicine would take this possibility as an argument in favor of neonatal labiaplasty. Indeed, such statements as “she won't even remember it,” “she'll heal faster,” “her future sexual partners will find her genitals to be more appealing,” and “it's relatively less risky at this age” (see box 1)—all of which are commonly invoked in defense of infant male circumcision—would be considered problematic. The expectation thus appears to be that girls should be able to make such personal decisions for themselves when they are older and can understand what is at stake.

NOTES

Materials in this box are adapted from text in the essay “Circumcision, Sexual Experience, and Harm,” which should be consulted for primary source citations; B.D. Earp and R. Darby, “Circumcision, Sexual Experience, and Harm,” *University of Pennsylvania Journal of International Law* 37, no. 2 (online 2017): 1-56.

1. A. Carmack, L. Notini, and B.D. Earp, “Should Surgery for Hypospadias Be Performed before an Age of Consent?” *Journal of Sex Research* 53, no. 8 (2016): 1047-58, 1057.

values for the unknown, individually and culturally variable preferences and values of future boys and men. It is for this reason that careful consideration of the influences that may have played into those subjective factors is needed.

The Charge of Cultural Bias

Noting that the conclusions of the AAP Task Force were “far from those reached by physicians in most other Western countries,”²⁶ the authors of the international critique raised the prospect of cultural bias²⁷ as a possible explanation: “Seen from

other pediatric societies and associations worldwide as being scientifically untenable.”³² And in 2016 the Danish Medical Association released a statement characterizing nontherapeutic male circumcision as being sufficiently risky that it should “only be performed on children when there is a documented medical need.”³³

Nevertheless, the AAP Task Force contested the charge of cultural bias in a response piece. The critical passage from their reply is as follows: “All of [our critics] hail from Europe, where the vast majority of men are uncircumcised and the cultural norm

Noting that the conclusions of the AAP Task Force were “far from those reached by physicians in most other Western countries,” the authors of the international critique raised the prospect of cultural bias as a possible explanation.

the outside, cultural bias reflecting the normality of nontherapeutic male circumcision in the United States seems obvious.”²⁸ They went on to state that in “Europe, Canada, and Australia, where infant male circumcision is considerably less common than in the United States, the AAP report is unlikely to influence circumcision practices,” because again, “the conclusions of the report and policy statement seem to be strongly culturally biased.”²⁹

Recent events appear to support this prediction. For example, the 2015 policy on newborn circumcision from the Canadian Pediatric Society, which has historically endorsed the position of the AAP, instead rejected it, failing to conclude that the benefits of infant circumcision outweigh the risks.³⁰ Similarly, upon revisiting its 2010 policy in light of the AAP findings, the Royal Australasian College of Physicians reaffirmed its view that “the frequency of diseases modifiable by circumcision, the level of protection offered by circumcision and the complication rates of circumcision do not warrant routine infant circumcision in Australia and New Zealand.”³¹

In addition, the president of Germany’s pediatric society, the Berufsverband der Kinder- und Jugendärzte, stated in a government hearing that “there is no reason from a medical point of view to remove an intact foreskin from underage boys or boys unable to give consent,” adding that “the statement from the AAP [has] been graded by almost all

clearly favors the uncircumcised penis. In contrast, approximately half of US males are circumcised, and half are not. Although that heterogeneity may lead to a more tolerant view toward circumcision in the United States than in Europe, the cultural ‘bias’ in the United States is much more likely to be a neutral one than that found in Europe, where there is a clear bias against circumcision.”³⁴

Our aim for the rest of this article is to assess this response by the AAP Task Force. Was the task force successful in dispelling the charge, levied by its international critics, that its evaluation of the medical literature may have been unduly influenced by cultural or other extrascientific factors? We consider the key claims of the AAP Task Force in turn.

DISCUSSION

The first claim of the AAP Task Force concerns differing cultural norms surrounding circumcision between the U.S. and Europe. In this context, we begin by correcting the assertion that all of the authors of the international commentary “hailed from Europe.” In fact, one of the signatories was the Canadian pediatrician Noni MacDonald, a member of the Canadian Academy of Health Sciences, founding editor of *Pediatrics & Child Health*, and the first woman to become a dean of medicine in Canada.³⁵ However, the other signatories were indeed from Europe, where, according to the AAP Task Force

members, “the vast majority of men are uncircumcised and the cultural norm clearly favors the uncircumcised penis.”³⁶ This claim inspires two observations that require further discussion.

Norms, Values, and Terminology

First, the AAP Task Force uses the term “uncircumcised” to describe whole or intact male genitalia. All normally developing boys are born with a foreskin, and most boys and men around the world do not have a surgically modified penis.³⁷ Despite this fact, the term “uncircumcised” frames circumcision as the default status, and recasts the natural penis as the linguistically marked category.³⁸ For a point of comparison, the AAP does not refer to infant girls’ vulvae as “unlabiaplastied.”³⁹ In other words, the choice of terminology employed by the AAP Task Force appears to reflect the prevailing cultural assumption(s) under which it was operating: namely, that the normative status for males is to be circumcised, rather than genitally intact.

The second observation has to do with the AAP Task Force’s reference to a “cultural norm” in Europe, which “clearly favors” the intact penis. Given the comparative rarity of nontherapeutic circumcision outside of minority religious groups in European countries,⁴⁰ it is certainly possible that a norm exists that favors surgically unmodified male genitalia. However, a similar “norm” exists throughout Europe that favors surgically unmodified female genitalia, as well as surgically unmodified body parts generally. In other words, it is unclear whether the lack of a tendency to excise nondiseased tissue, whether from the body of a child or an adult, is the sort of thing that should be described as a “norm,” unless all nonperformed actions are eligible to be called “norms” if their nonperformance is typical in some group.

But let us simply grant that there is a “cultural norm” in Europe that “clearly favors” the intact penis. It does not follow from this, as the AAP Task Force implies, that its European counterparts are “biased” against circumcised penises. This is because, whatever the wider cultural norm concerning circumcision happens to be in Europe, there is also a relevant *medical* norm, not only in Europe, but also in the U.S., which holds that (1) medically unnecessary surgeries should generally not be performed on healthy children, and (2) surgery should almost always be a last resort, rather than a first resort, for managing or preventing disease.⁴¹

Thus, it is not just a matter of two local, arbitrary cultural norms being pitted against one another. Rather, the *shared* norms governing responsible

medical practice in Western countries are typically “biased” against such nontherapeutic procedures. Accordingly, by suggesting that a cultural norm that favors the nontherapeutic surgical modification of a child’s penis “is somehow on par with, or just as reasonable as, a medical-ethical norm favoring the avoidance of such surgery unless it is absolutely required,” the AAP Task Force could be seen as revealing its cultural hand.⁴²

Indeed, only the U.S. and Israel, among Western developed nations, maintain a majority practice of routine neonatal male circumcision.⁴³ In the latter case, the explanation for the practice is predominantly religious, being derived from a perceived scriptural mandate along with a historically rooted sense of shared Jewish identity, of which male circumcision in infancy is a symbol.⁴⁴ The historical process by which ritual circumcision became “medicalized” in the U.S.—and later entrenched as a wider cultural practice—has been documented elsewhere.⁴⁵ The point here is that the unique position of the U.S. medical establishment in favoring the nonreligious circumcision of male newborns suggests that it is the AAP Task Force, rather than its critics, that bears the greater burden in justifying its background cultural norms.

This view is further supported by research on “cultural cognition.” As Yale psychologist Dan Kahan explains, a major tenet of cultural theory is that “individuals gravitate toward perceptions of risk that advance the way of life to which they are committed.”⁴⁶ According to this view, moral concern guides not only response to risk, but also the basic faculty of risk perception.⁴⁷ Thus, each way of life and associated worldview “has its own typical risk portfolio,” that “shuts out perception of some dangers and highlights others” in ways that selectively sustain the norms and practices to which one is most deeply devoted.⁴⁸

With respect to the debate over cultural bias between the members of the AAP Task Force and their international critics, it is difficult to see how “not circumcising” would meet the criteria for being a distinctive component of a “worldview” or a “way of life” that might directly influence the risk perception of the mostly European group of doctors. In other words, while circumcising infant boys is (1) an entrenched birth custom in American culture that is deeply tied up with implicit and explicit notions of “good parenting,”⁴⁹ and (2) a central ritual practice within Judaism and Islam, it is less clear in what sense “not circumcising” is (or could be) either an entrenched birth custom or a central ritual practice in “European” culture. In fact, it is by defi-

inition not a practice, but the lack of one. Moreover, this lack of practice is not closely associated with “European” cultural identity in any specific, coherent sense: rather, it is simply one of a large number of rituals and other practices that is not particularly common in Europe.

A Child’s Right to Physical Integrity

To see how anomalous the U.S. medical community’s support for newborn male circumcision is, it may be useful to consider the nearest anatomical analog, namely, the nontherapeutic surgical modification of female genitalia (for example, for cultural or religious reasons).⁵⁰ Not only is such surgery normatively discouraged before an age of consent in Western medicine, but it is strictly forbidden by national and international law, primarily on the grounds that it violates a child’s right to physical integrity.⁵¹ According to the World Health Organization (WHO), this right is violated (see box 3) by all medically unnecessary alteration of the female genitalia, no matter how superficial or hygienically performed.⁵² As a consequence, Western prohibitions of such genital alteration extend even to those forms that are significantly less invasive than male circumcision. This includes ritual “pricking” of the clitoral hood—FGM WHO Type 4—that does not remove tissue, rarely leads to long-term adverse health consequences, and is often carried out by trained healthcare providers in sterile settings.⁵³

To explain this apparent discrepancy in treatment regarding male versus female children, the AAP Task Force argues that “the right to physical

integrity is easier to defend in the context of a procedure that offers no potential benefit.”⁵⁴ This is presumed to be the case for nontherapeutic female genital cutting (FGC). However, this response deserves closer scrutiny.

First, the “potential benefit” to which the AAP Task Force refers in this sentence is “medical benefit” or “health benefit.” However, in the case of male circumcision, the AAP Task Force shows a willingness to consider potential nonmedical—that is, sociocultural—benefits as well, stating that “it is reasonable to take these nonmedical benefits . . . into consideration when making a decision about circumcision.”⁵⁵ As the British Medical Association (BMA) notes, “Where a child is living in a culture in which circumcision is [believed to be] required for all males, [exclusion] may cause harm by, for example, complicating the individual’s search for identity and sense of belonging.”⁵⁶ However, the BMA also notes that “very similar arguments are also used to try and justify very harmful cultural procedures, such as female genital mutilation or ritual scarification. Furthermore, the harm of denying a person the opportunity to choose not to be circumcised must also be taken into account, together with the damage that can be done to the individual’s relationship with his parents and the medical profession if he feels harmed by the procedure.”⁵⁷

Second, it may never be known whether a minor, sterilized form of FGC—such as neonatal labiaplasty—would offer a “potential benefit” in the sense implied by the AAP Task Force, because it would be illegal to conduct a properly controlled

BOX 3. A Child’s Right to Physical Integrity: How Should it Be Applied?

A child’s right to physical integrity is not absolute. Interventions that are clearly in the child’s best interests, especially if they cannot be delayed until the child is competent to consent or decline (for example, emergency surgery to correct a heart defect) are universally agreed to be permissible. Trivial, superficial, or easily reversible interventions (for example, getting a haircut), or more serious, risky, or permanent interventions to which the child can give age-appropriate consent (for example, cosmetic orthodontia, participating in sports), are also usually permissible. However, the mere fact that children are pre-autonomous and cannot validly consent to most interventions, “medical” or otherwise, that affect their bodies (for example, being forced to eat their vegetables) does not entail that parents have an unfettered right to authorize all such interventions (for example, child sexual abuse). The less clear it is that a bodily encroachment is, all things considered, in the child’s best interests (taking into account the child’s interest in being able to autonomously make important self-affecting decisions in the future), the more likely it is that the child’s bodily integrity rights are being impermissibly violated.

NOTES

Some material in this box is adapted from B.D. Earp, “The AAP Report on Circumcision: Bad Science + Bad Ethics = Bad Medicine,” *Practical Ethics*, 29 August 2012, <http://blog.practicaethics.ox.ac.uk/2012/08/the-aap-report-on-circumcision-bad-science-bad-ethics-bad-medicine/>.

scientific study to secure the answer.⁵⁸ But one cannot rule the possibility of health benefits out.⁵⁹ Cancers of the labia, for instance, might be less likely to occur in someone whose labia have been surgically reduced, due to the decreased surface area of the relevant tissue.⁶⁰ Indeed, removing *any* healthy tissue from a child's body would likely reduce the risk of some disease that might otherwise affect that tissue, or other parts of the body through it.⁶¹

And yet, the mere prospect of some health benefit following from the removal of healthy tissue is not normally seen as sufficient grounds for overriding a child's right to physical integrity.⁶² This principle holds true especially when there are alternative ways to achieve the same health benefit that do not involve surgery and its attendant risks—a consideration that applies to all of the health benefits that have been attributed to male circumcision.⁶³ Adding to this is the “private” nature of the body part in question, about which people have strong and often conflicting emotions (compare with, for example, the tonsils, which are in any case no longer routinely removed).⁶⁴ Given such strong emotions, the permanency of circumcision, and the special significance of the penis as compared to other parts of the body, it seems preferable to defer the surgery, all else being equal, until the person whose body will be affected by it is in a position to decide what is best for him.⁶⁵

It is sometimes argued that infant male circumcision meets the “trivial” condition mentioned in box 3, and thus fails to rise to the level of a rights violation. Often, this argument is made by analogy with piercing the ear lobes of female infants: if the latter is permissible, why not the former?⁶⁶ There are two ways to respond to this argument. The first way is to suggest that perhaps ear piercing, too, should not be performed before the affected child can weigh in. If she understands that it will be painful, that there are certain risks involved, *et cetera*, and yet this is still something she would like to undertake, then it should be allowed.

The second way is to point out that the two practices—piercing infants' ears and infant male circumcision—are not commensurate. Ear piercing removes no tissue, it (minimally) alters a part of the body that is less sensitive both physically and symbolically, it creates a wound that is much smaller, and it is often reversible: the hole may close up over time if the child later decides that he or she would like to have earlobes free of holes. By contrast, infant male circumcision removes up to half of the motile skin system of the penis⁶⁷ (approximately 30 to 50 square centimeters of erogenous tissue in the average adult

organ),⁶⁸ excises the portion of the penis that is most sensitive to light touch,⁶⁹ precludes all sexual activities that require manipulation of the foreskin,⁷⁰ and is irreversible: anyone who resents having had his foreskin removed cannot recover what was lost.

Nonmedical Motivations

Most of our discussion thus far has focused on the prospect of health benefits. But this is not the original reason for the practice of male circumcision, nor is it the main reason for its continuance today. As AAP Task Force member Andrew Freedman, MD, stated in a recent editorial: “Most circumcisions are done due to religious and cultural tradition. In the West, although parents may use the conflicting medical literature to buttress their own beliefs and desires, for the most part parents choose what they want for a wide variety of nonmedical reasons. There can be no doubt that religion, culture, aesthetic preference, familial identity, and personal experience all factor into their decision. Few parents when really questioned are doing it solely to lower the risk of urinary tract infections or ulcerative sexually transmitted infections.”⁷¹

In support of this observation, Freedman stated in a separate interview that he had circumcised his own son. “But I did it for religious, not medical reasons,” he stated. “I did it because I had 3,000 years of ancestors looking over my shoulder.”⁷²

What relevance might this statement have for the debate over cultural bias? As Dan Kahan explains, when one's identity or standing in an affinity group depends at least partially on one's stance toward certain empirical matters, this can “generate motivated cognition relating to policy-relevant facts.”⁷³ Such cognition does not require conscious awareness: “Even among modestly partisan individuals, shared ideological or cultural commitments are likely to be intertwined with membership in [certain] communities. . . . If a proposition about some policy-relevant fact comes to be commonly associated with membership in such a group, the prospect that one might form a contrary position can threaten one's standing within it. Thus . . . individuals are unconsciously motivated to resist empirical assertions [if] those assertions run contrary to the dominant belief within their groups.”⁷⁴

Consistent with this view, as Jonathan Koehler has described, fabricated research reports that appear to agree with scientists' prior beliefs are judged to be of higher quality than those that disagree, despite controlling for actual quality.⁷⁵ One possible explanation for more favorable appraisals in the “agree” condition is that scientists may “differen-

tially scrutinize” studies that yield belief-congruent versus belief-incongruent findings. Thus, Koehler argues, “Studies that are known to have yielded belief-congruent data may be examined less carefully for having obtained the ‘correct’ result, and may be presumed to have been conducted properly. On the other hand, when scientists evaluate studies that are not known to have produced ‘correct’ results . . . their suspicion that something may be wrong with the study is heightened.”⁷⁶

In line with this possibility, it is reasonable to think that a prior religious belief in the desirability of circumcision could—at least in principle—unconsciously influence one’s perception of a study’s relevance, methodological rigor, and clarity of results (as in the Koehler experiments) in such a way that the perceived quality of circumcision-supportive findings, compared to nonsupportive findings, would be inappropriately inflated.⁷⁷

Another potential source of bias stems from the findings of a 2010 survey of 572 Canadian physicians by Andries Muller. “Although most respondents stated that they based their decisions on medical evidence,” Muller discovered, “the circumcision status of, especially, the male respondents played a huge role in whether they were in support of circumcisions or not. Another factor that had an influence was the circumcision status of the respondents’ sons.”⁷⁸ Specifically, 68.3 percent of the circumcised males were in support of newborn male circumcision, whereas 68.8 percent of the noncircumcised males were opposed to it. In addition, 77.2 percent of those respondents whose sons were circumcised were in support of circumcision, whereas 64.7 percent of those whose sons were not circumcised were opposed to it.

Motivated Reasoning

How might these findings be explained? One possibility is that a doctor who was himself circumcised before he could consent or decline, or who has had his son circumcised under the same conditions, might be more likely than a doctor to whom these considerations do not apply to engage in a form of “motivated reasoning.”⁷⁹ Specifically, he may be motivated, whether consciously or unconsciously, to evaluate the murky and heavily contested medical evidence concerning circumcision in such a way that his decision regarding his son—or his own circumcision status—can be independently justified on grounds of net benefit.⁸⁰

This explanation is consistent with the well-supported theory of cognitive dissonance from the field of psychology.⁸¹ If the medical evidence sug-

gests that newborn circumcision is a net harm, or at least not a significant benefit, then a man who has already been circumcised—or who has had his son circumcised—will be confronted with a distressing thought: either that his parents did something to him that they probably ought not to have done (all else being equal), or that he has done something to his own son that he probably ought not to have done (all else being equal), or both.⁸²

The key here is that being circumcised (lacking a foreskin), as opposed to not being circumcised (possessing a foreskin), is irreversible. In other words, if something is a net harm, but cannot be undone, cognitive dissonance theory suggests that the mind will do whatever it can to reframe what has taken place as a benefit. By contrast, if something can be undone—such as the state of not being circumcised—then there is much less likely to be cognitive dissonance in the first place in need of resolution, including in the possible form of a motivated interpretation of the empirical literature. Since it is likely that the circumcision status of the American versus European doctors (or that of their sons) is asymmetrical in this regard, this theoretical difference in cognitive dissonance may be of relevance to this debate.⁸³

The 50-50 Defense

We turn now to a further claim made by the AAP Task Force, namely that “approximately half of US males are circumcised, and half are not” such that any “‘bias’ regarding circumcision in the United States is much more likely to be a neutral one.”⁸⁴ How compelling is this response to the charge of cultural bias?

First, it is unclear on what grounds the AAP Task Force members base their assertion that approximately half of U.S. males are circumcised. According to the AAP’s own technical report, from 1999 to 2010, the approximate percentage of newborn U.S. males who were circumcised ranged from 55.8 percent to 59.1 percent depending on the source. But these incidence rates “were derived from hospital-based surveys and do not include out-of-hospital circumcisions; thus, these data sources underestimate the actual rate of newborn male circumcision in the first month of life.”⁸⁵ Such undercounting suggests that the current incidence of circumcision is more likely to be 60 percent or higher. However, that is not the most relevant statistic. More relevant would be the prevalence of circumcision, which factors in older men who were born in earlier decades when circumcision was more common, and whose attitudes would also need to be considered. The fig-

ure for prevalence has most recently been estimated to be more than 80 percent.⁸⁶

But let us just assume, contrary to this evidence, that approximately 50 percent of U.S. males are circumcised, either in terms of the current rate or the current prevalence. It is a *non sequitur* to assert that *attitudes* toward circumcision in the U.S. are 50 percent favorable, equally tolerant of circumcised and noncircumcised penises, or otherwise “neutral” as the AAP Task Force implies. Cultural attitudes take time to change, and the implication of a recent

as dispassionately as possible, the empirical evidence concerning the benefits and risks associated with newborn circumcision. Whether parents do or should have a right to authorize circumcision is an important and difficult question, and it is one that moral philosophers, bioethicists, legal theorists, and others are attempting to answer. But it seems fair to suggest that it is not a question that should inform, much less consciously and deliberately inform, a scientific report on the medical consequences of newborn male circumcision.

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drop in the rate or prevalence of circumcision for prevailing attitudes is unclear.

The more relevant question is narrower in scope. In judging whether the conclusions of the AAP Task Force were biased or unbiased with respect to the medical evidence concerning the circumcision of newborn males, it is not especially informative to allude to the percentage of circumcised men in the population at large. Instead, it seems important to determine the attitudes of the members of the AAP Task Force themselves—that is, the ones who reviewed the literature.

Evidence of such attitudes may be found in the 2016 editorial by Andrew Freedman. Referring explicitly to nonscientific political considerations, Freedman stated that “protecting” the parental option to circumcise “was not an idle concern” in the minds of the AAP Task Force members “at a time when there are serious efforts in both the United States and Europe to ban the procedure outright.”⁸⁷ The reference appears to be to a failed 2011 ballot initiative in San Francisco that sought to criminalize nontherapeutic circumcision before the age of 18, and to a 2012 Cologne court judgment—later overturned by the German legislature—finding that circumcision of male minors without a medical indication constitutes bodily assault.⁸⁸

In this context, one may wonder whether protecting the parental option to circumcise should in fact have been an idle concern. As we understand it, the remit of the AAP Task Force was to evaluate,

Liberal societies depend on scientific personnel to provide unbiased, apolitical analyses of “the facts” pertaining to their public deliberations. This goal is difficult to achieve in practice, as scientists are not immune from personal, cultural, and other biasing factors even in the best of circumstances, as we have noted.⁸⁹ But it is widely held that scientific analysts should do their best to neutralize such factors, using the most effective means available. Seemingly, a scientific committee that sees itself as engaged, however tangentially, in “protecting” a contested cultural or religious rite (an aim with respect to which a finding of net medical benefit would presumably be auspicious) has not done its best in this regard.

A Note on Ethics—and Equipoise

We are not certain that it is appropriate for the AAP or any similar medical organization to opine on the ethics of circumcising male newborns:⁹⁰ if the question is about benefits and risks, these should be documented clearly and thoroughly, based solely upon the empirical data. Moreover, if weights or values are to be assigned, these should be assigned by the person contemplating the surgery in light of his own preferences and values, as we have argued; a policy committee is not best qualified to make such judgments for others.

If, however, an ethical discussion is to be included in a scientific report, it is desirable that more than one perspective be represented. In the context

of a debate that is as polarized as the one on circumcision of infant males,⁹¹ it is notable that the single bioethicist appointed to the AAP Task Force, Douglas Diekema, MD, had already made his views on the subject clear, previously arguing in favor of the permissibility not only of male forms of circumcision, but also certain female forms of ritualized genital cutting, despite near-universal condemnation of the latter.⁹²

This sole appointment is notable because the view that neither male nor female children deserve absolute protection from having their genitals cut for nontherapeutic reasons is an outlier position among policy experts. Moreover, the “harm principle” promoted by Diekema, which explicitly favors expansive parental rights over the advancement of children’s best interests, is similarly contentious.⁹³ It is reasonable to think that a committee with as much influence as the AAP Task Force would strive to include a diversity of voices in its ethical discussions.

There are legitimate arguments to be made that newborn male circumcision should be considered morally and/or legally acceptable.⁹⁴ One could even argue that religious circumcision in particular should be tolerated *even if* it is a net (medical) harm, since there are numerous factors at play in such determinations apart from risk-benefit assessments. However, the moral and legal status of nontherapeutic procedures to alter genitals has become increasingly controversial in the past few decades, with a growing contingent of scholars maintaining that all such procedures performed on children (male, female, and intersex) should be discouraged, if not forbidden.⁹⁵

Therefore, to achieve a properly balanced consideration of the opposing viewpoints, future committees in this area should consider appointing at least two ethicists who represent the range of current thinking on the issue. The dialectic between them, it is hoped, would yield a more nuanced and comprehensive ethical discussion than was evidenced in the 2012 AAP documents. As J. Steven Svoboda and Robert Van Howe have stated, these documents

fail to mention foundational principles from biomedical ethics. Seemingly, such notions as respect for autonomy, a child’s right to an open future, and the normally high bar set for surgical interventions on minors would be at least worth *alluding to* in a serious discussion of the moral permissibility of male circumcision. Yet the AAP’s repeated, unsupported, alternative suggestion that, “In most situations, parents are

granted wide latitude in terms of the decisions they make on behalf of their children” constitutes its entire ethical argument.⁹⁶

Svoboda and Van Howe overstate their case, because the AAP Task Force does mention that parents and physicians have an “ethical duty to the child to attempt to secure the child’s best interests and well-being.”⁹⁷ However, the immediate next move of the AAP Task Force is to emphasize that reasonable people disagree as to what is in a child’s best interests (see box 1), leading them to the “alternative suggestion” mentioned by Svoboda and Van Howe. In other words, given that people have different judgements about what best promotes a child’s well-being, the AAP Task Force suggests that parents should normally be allowed to take or authorize any action whatsoever toward their child, unless it is “clearly contrary to the best interests of the child or places the child’s health, well-being, or life at significant risk of serious harm.”⁹⁸

A problem with this view is that, just as reasonable people may disagree about what is in a child’s best interests, reasonable people may also disagree about what is clearly *contrary* to a child’s best interests, and about what places the child’s health, *et cetera*, at “significant risk of serious harm.” Removing part of a child’s genitals in the absence of a clear medical need is the very sort of thing that many reasonable people do regard as a serious harm, regardless of whether there may also be certain modest health benefits that follow from such removal.⁹⁹ So what does this analysis suggest about the limits, if any, there should be on parental behavior? If reasonable people may disagree not only about “best interests,” but also about “serious harm,” then a practical implication of the AAP’s proposal seems to be that parental decision making should remain essentially unfettered.

It is commonly accepted that, “in most situations,” parents are (and should be) permitted to make decisions on behalf of their children (see box 3). But in the context of Western medicine, at least, one could also argue that nontherapeutic genital surgery is not “most situations.” In other words, while it may be accurate to say that parents generally have “wide latitude” in bringing up their children as they see fit, it is also true that societies may justifiably place certain restrictions on parental actions, particularly when it comes to irreversible body modifications that a child may later regard as a harm.

To illustrate: in some jurisdictions, tattooing a child’s body is not permitted, even when the parents believe that being tattooed is in a child’s best

interests. With respect to the United Kingdom, for instance, as James Chegwidan notes, “the common law is very cautious before treating [even] children’s consent as justifying any non-therapeutic body alteration.”¹⁰⁰ Indeed, in British parliamentary debates regarding a proposed ban on tattooing prior to age 18, concerns were raised that “apply almost *identically* to the arguments voiced about circumcision, namely: the existence of persons who later regret having the procedure done; the difficulty of reversing the procedure; the danger of infections and other complications arising from the tattooing procedure; [. . .] the embarrassment felt by those tattooed who later regret it; the unhygienic conditions in which some tattooing is performed [and so on].”¹⁰¹

Failure to consistently apply this reasoning may lead to peculiar results. For instance, while parents would not be allowed to tattoo their son’s foreskin for nontherapeutic reasons in such jurisdictions, they *would* be allowed to have his foreskin completely removed for nontherapeutic reasons, and then tattooed. This example provides further evidence that newborn male circumcision occupies an anomalous position in Western (medical) culture.

Perhaps even more relevant than tattooing, however, as we have already noted, is the practice of nontherapeutic FGC. In Western societies, including the U.S., parents may not cut into, much less excise, any part of a female child’s genitalia when it is deemed medically unnecessary to do so. Crucially, this is the case even when (1) the cutting is less extensive, risky, or harmful than male circumcision; (2) the parents sincerely believe it is required by their religion; and (3) it is likely to confer significant social benefit on the child, due to the prevailing beliefs, attitudes, and expectations of the community in which she is being raised.¹⁰²

In order to determine whether any particular nontherapeutic alteration of a child’s body is ethically and perhaps also legally acceptable, therefore, it is not enough to invoke a vague conception of “serious harm” (such that, for any action X, an interested party could plausibly argue that it is “not harmful enough” to warrant state interference), nor to refer to the “wide latitude” that is typically granted to parents. Instead, it is necessary to triangulate between analogous cases to determine where the limits should lie.

CONCLUSION

As Shaw has argued, a near-exclusive focus in the medical literature on potential biases stemming from financial conflicts of interest “has tended to

obscure the fact that other biasing factors can seriously compromise an author’s impartiality and objectivity.”¹⁰³ In the present context, we have argued that one such potentially biasing factor is whether one has been circumcised oneself, or has circumcised his or her son.¹⁰⁴ Because circumcision is irreversible, there is likely to be a strong motive among such persons to reach the conclusion that it is desirable, on balance, to be circumcised. For if it is not desirable on balance, there are few, if any, options for “undoing” what has already been done.

Moreover, having a personal or political stake in the circumcision of male infants, whether on religious or other grounds, could play a biasing role.¹⁰⁵ While individual AAP Task Force members may feel free to lobby for legal or other protections for nontherapeutic circumcision as private citizens, they should not allow such political ends to enter into their evaluations of the science. Moreover, a concerted effort should be made to balance out whatever political, moral, or other normative viewpoints there are among committee members, by appointing not only proponents of circumcision, but also critics. More generally, whenever professional medical or ethical opinion is polarized, qualified representatives of both poles should be included in the relevant scientific and policy discussions.

NOTES

1. AAP, “Circumcision Policy Statement,” *Pediatrics* 130, no. 3 (2012): 585-86; AAP, “Male Circumcision (Technical Report),” *Pediatrics* 130, no. 3 (2012): e756-85, e757.

2. E. Shapiro, “American Academy of Pediatrics Policy Statements on Circumcision and Urinary Tract Infection,” *Reviews in Urology* 1, no. 3 (1999): 154-56; S.E. Waldeck, “Using Male Circumcision to Understand Social Norms as Multipliers,” *University of Cincinnati Law Review* 72 (2003): 455-526.

3. See, e.g., KNMG, “Nontherapeutic Circumcision of Male Minors,” *Royal Dutch Medical Association-KNMG* (2010), <https://www.circumstitions.com/Docs/KNMG-policy.pdf>; RACP, “Circumcision of Infant Males,” *Royal Australasian College of Physicians* (2010) (including a summary of position statements from other medical bodies in the appendix), https://www.racp.edu.au/docs/default-source/advocacy_library/circumcision-of-infant-males.pdf; see also more recently, Canadian Paediatric Society, “Newborn Male Circumcision,” *Paediatrics & Child Health* 20, no. 6 (2015): 311-320; and see C. England, “Doctors in Denmark Want to Stop Circumcision for Under-18s,” *Independent*, 7 December 2016.

4. Various critiques in addition to those listed in table 1 were also raised: see the references collected in B.D. Earp, “Do the Benefits of Male Circumcision Outweigh the Risks? A Critique of the Proposed CDC Guidelines,” *Frontiers in Pediatrics* 3, no. 18 (2015): 1-6. Note that re-

sponses and counter-responses to some of these critiques are available at the relevant journal websites.

5. M. Frisch et al., "Cultural Bias in the AAP's 2012 Technical Report and Policy Statement on Male Circumcision," *Pediatrics* 131, no. 4 (2013): 796-800, 796.

6. AAP, "Male Circumcision (Technical Report)," see note 1 above.

7. Frisch et al., "Cultural Bias," see note 5 above, p. 776.

8. N. Bostrom and T. Ord, "The Reversal Test: Eliminating Status Quo Bias in Applied Ethics," *Ethics* 116, no. 4 (2006): 656-79.

9. RACP, "Circumcision of Infant Males," see note 3 above.

10. I. Sneppen and J. Thorup, "Foreskin Morbidity in Uncircumcised Males," *Pediatrics* 137, no. 5 (2016): e20154340; see also M. Frisch and B.D. Earp, "Circumcision of Male Infants and Children as a Public Health Measure in Developed Countries: A Critical Assessment of Recent Evidence," *Global Public Health*, in press.

11. B.J. Morris, S.A. Bailis, and T.E. Wiswell, "Circumcision Rates in the United States: Rising or Falling? What Effect Might the New Affirmative Pediatric Policy Statement Have?" *Mayo Clinic Proceedings* 89, no. 5 (2014): 677-86, 678. But see I. Jenkins, "Bias and Male Circumcision," *Mayo Clinic Proceedings* 89, no. 5 (2014): 677-86.

12. AAP, "Male Circumcision (Technical Report)," e772, see note 1 above. "The true incidence of complications after newborn circumcision is unknown, in part due to differing definitions of 'complication' and differing standards for determining the timing of when a complication has occurred (i.e., early or late). Adding to the confusion is the comingling of 'early' complications, such as bleeding or infection, with 'late' complications such as adhesions and meatal stenosis. Also, complication rates after an in-hospital procedure with trained personnel may be far different from those of the developing world and/or by untrained ritual providers."

13. See, e.g., G.J. Boyle et al., "Male Circumcision: Pain, Trauma, and Psychosexual Sequelae," *Journal of Health Psychology* 7, no. 3 (2002): 329-43; T. Hammond and A. Carmack, "Long-Term Adverse Outcomes from Neonatal Circumcision Reported in a Survey of 1,008 Men: An Overview of Health and Human Rights Implications," *International Journal of Human Rights* 21, no. 2 (2017): 189-218.

14. F. Schwaller and M. Fitzgerald, "The Consequences of Pain in Early Life: Injury-Induced Plasticity in Developing Pain Pathways," *European Journal of Neuroscience* 39, no. 3 (2014): 344-52; AAP, "Prevention and Management of Procedural Pain in the Neonate: An Update," *Pediatrics* 137, no. 2 (2016): e20154271; G. Page, "Are There Long-Term Consequences of Pain in Newborn or Very Young Infants?" *Journal of Perinatal Education* 13, no. 3 (2004): 10-17; A.N. Schore, "All Our Sons: The Developmental Neurobiology and Neuroendocrinology," *Infant Mental Health Journal* 38, no. 1 (2017): 15-52; M. Frisch and J. Simonsen, "Ritual Circumcision and Risk of Autism Spectrum Disorder in 0- to 9-Year-Old Boys: Na-

tional Cohort Study in Denmark," *Journal of the Royal Society of Medicine* 108, no. 7 (2015): 266-79; M. Frisch and J. Simonsen, "Circumcision-Autism Link Needs Thorough Evaluation: Response to Morris and Wiswell," *Journal of the Royal Society of Medicine* 108, no. 8 (2015): 297-98.

15. P.J. Ball, "A Survey of Subjective Foreskin Sensation in 600 Intact Men," in *Bodily Integrity and the Politics of Circumcision* (New York: Springer, 2006), 177-88; R. Darby and L. Cox, "Objections of a Sentimental Character: The Subjective Dimensions of Foreskin Loss," *Matatu-Journal for African Culture and Society* 37, no. 1 (2009): 145-68; S. Johnsdotter, "Discourses on Sexual Pleasure after Genital Modifications: The Fallacy of Genital Determinism (a Response to J. Steven Svoboda)," *Global Discourse* 3, no. 2 (2013): 256-65; J. Richters, "Bodies, Pleasure and Displeasure," *Culture, Health & Sexuality* 11, no. 3 (2009): 225-36; B.D. Earp, "Infant Circumcision and Adult Penile Sensitivity: Implications for Sexual Experience," *Trends in Urology & Men's Health* 7, no. 4 (2016): 17-21; B.D. Earp, "Sex and Circumcision," *American Journal of Bioethics* 15, no. 2 (2015): 43-45.

16. L. Brotto et al., "Psychological and Interpersonal Dimensions of Sexual Function and Dysfunction," *Journal of Sexual Medicine* 13, no. 4 (2016): 538-71.

17. A. McMath, "Infant Male Circumcision and the Autonomy of the Child: Two Ethical Questions," *Journal of Medical Ethics* 41, no. 8 (2015): 687-90; H. Maslen et al., "Brain Stimulation for Treatment and Enhancement in Children: An Ethical Analysis," *Frontiers in Human Neuroscience* 8, no. 953 (2014): 1-5.

18. A.L. Freedman, "The Circumcision Debate: Beyond Benefits and Risks," *Pediatrics* 137, no. 5 (2016): e20160594.

19. See discussion in R.S. Van Howe, "The American Academy of Pediatrics and Female Genital Cutting: When National Organizations Are Guided by Personal Agendas," *Ethics & Medicine* 27, no. 3 (2011): 165-74.

20. McMath, "Infant Male Circumcision and the Autonomy of the Child," see note 17 above, p. 689.

21. *Ibid.*

22. See generally, D.M. Kahan, "Ideology, Motivated Reasoning, and Cognitive Reflection: An Experimental Study," *Judgment and Decision Making* 8, no. 4 (2013): 407-21; J.J. Koehler, "The Influence of Prior Beliefs on Scientific Judgments of Evidence Quality," *Organizational Behavior and Human Decision Processes* 56, no. 1 (1993): 28-55.

23. Hammond and Carmack, "Long-Term Adverse Outcomes," see note 13 above; Ball, "A Survey of Subjective Foreskin Sensation," see note 15 above; B.D. Earp and R. Darby, "Circumcision, Sexual Experience, and Harm," *University of Pennsylvania Journal of International Law* 37, no. 2 (online 2017): 1-56.

24. R. Darby, "Risks, Benefits, Complications and Harms: Neglected Factors in the Current Debate on Non-Therapeutic Circumcision," *Kennedy Institute of Ethics Journal* 25, no. 1 (2015): 1-34.

25. J. Bossio, C. Pukall, and K. Bartley, "You Either Have It or You Don't: The Impact of Male Circumcision

Status on Sexual Partners," *Canadian Journal of Human Sexuality* 24, no. 2 (2015): 104-19, 104.

26. For a more recent discussion, see M. Jansen, "Still Locked: A Reply to Wodak, Ziegler and Morris," *Journal of Paediatrics and Child Health* 53, no. 1 (2017): 93-4.

27. *Status quo bias*—i.e., in favor of continuing the practice of circumcision—would also apply in this case, although the international critics did not raise this issue. Another potential source of bias is what has been called *intervention bias*, namely, the tendency of doctors to favor taking action, including surgical action, when nonintervention is equally justified or more justified on strictly medical grounds: A.J. Foy and E.J. Filippone, "The Case for Intervention Bias in the Practice of Medicine," *Yale Journal of Biology and Medicine* 86, no. 2 (2013): 271-80. *Publication bias* may also play a role—the tendency of journals to favor publication of studies that appear to show a positive effect of the intervention in question, in this case circumcision: P.J. Easterbrook et al., "Publication Bias in Clinical Research," *Lancet* 337, no. 8746 (1991): 867-72; B.D. Earp, "The need for reporting negative results—a 90 year update," *Journal of Clinical and Translational Research* 3, no. 52 (2017): 1-4; B.D. Earp and P. Wilkinson, "The Publication Symmetry Test—A Simple Editorial Heuristic to Combat Publication Bias," *Journal of Clinical and Translational Research*, in press. Finally, *peer review bias* has also been mentioned as a possible factor: R.S. Van Howe, "Peer-Review Bias Regarding Circumcision in American Medical Publishing," in *Male and Female Circumcision* (New York: Springer US, 1999), 357-78.

28. Frisch et al., "Cultural Bias," see note 5 above, p. 796.

29. *Ibid.*

30. Canadian Paediatric Society, "Newborn Male Circumcision," see note 3 above.

31. RACP, "Circumcision of Infant Males," see note 3 above; see also K. Pringle, "Circumcision Health Risks and Benefits—Experts Respond," *Science Media Center*, 4 April 2014; D. Forbes, "Circumcision and the Best Interests of the Child," *Journal of Paediatrics and Child Health* 51, no. 3 (2015): 263-5; A.F. Na, T. Sharman, and J.M. Hutson, "Circumcision: Is It Worth It For 21st-Century Australian Boys?" *Journal of Paediatrics and Child Health* 51, no. 6 (2015): 580-3.

32. W. Hartmann, "Expert Statement: Dr Med. Wolfram Hartmann, President of 'Berufsverband Der Kinder-Und Jugendärzte' for the Hearing on the 26th of November 2012 Concerning the Drafting of a Federal Government Bill," 2012, http://www.intactamerica.org/german_pediatrics_statement.

33. As paraphrased in England, "Doctors in Denmark," see note 3 above. Please note that the British Medical Association is currently revising its guidelines; it is not known what position it will take.

34. AAP, "Cultural Bias and Circumcision: The AAP Task Force on Circumcision Responds," *Pediatrics* 131, no. 4 (2013): 801-4, 801.

35. Canadian Academy of Health Sciences/Académie Canadienne Des Sciences de La Santé, "Noni MacDonald," 5 April 2017, <http://cahs-acss.ca/noni-macdonald/>.

36. AAP, "Cultural Bias and Circumcision," see note 34 above, p. 801.

37. B.J. Morris et al., "Estimation of Country-Specific and Global Prevalence of Male Circumcision," *Population Health Metrics* 14, no. 4 (2016): 1-3; E. Wallerstein, "Circumcision: The Uniquely American Medical Enigma," *Urologic Clinics of North America* 12, no. 1 (1985): 123-32.

38. W.G. Wallace, "An Undeniable Need for Change: The Case for Redefining Human Penis Types: Intact, Circumcised, and Uncircumcised (All Three Forms Exist and All Are Different)," *Clinical Anatomy* 28, no. 5 (2015): 563-4; R.V. Hill, "Altered Anatomy Demands Dedicated Terminology: A Response to Wallace (2015)," *Clinical Anatomy* 28, no. 8 (2015): 960-1; W.G. Wallace, "An Undeniable Need for Recognition: What Do You Call a Man Who Has Undergone Foreskin Restoration? A Response to Hill (2015)," *Clinical Anatomy* 28, no. 8 (2015): 962-3.

39. It should be noted that in many cultures in which ritual female genital cutting is common and normative, girls with intact vulvae are also referred to (in English) as "uncircumcised," in many cases as an explicit pejorative. O. Bamgbose, "Women and the Law in Africa: Legal and Cultural Approaches to Sexual Matters in Africa: The Cry of the Adolescent Girl," *University of Miami International and Comparative Law Review* 10 (2001): 127-241; B. Shell-Duncan and Y. Hernlund, *Female "Circumcision" in Africa: Culture, Controversy, and Change* (Boulder, Colo.: Lynne Rienner, 2000).

40. Morris et al., "Estimation of Country-Specific and Global Prevalence of Male Circumcision," see note 37 above.

41. Na, Shaman, and Hutson, "Circumcision," see note 31 above.

42. B.D. Earp, "The AAP Report on Circumcision: Bad Science + Bad Ethics = Bad Medicine," *Practical Ethics*, 29 August 2012, <http://blog.practicaethics.ox.ac.uk/2012/08/the-aap-report-on-circumcision-bad-science-bad-ethics-bad-medicine/>.

43. Wallerstein, "Circumcision: The Uniquely American Medical Enigma," see note 37 above.

44. L.B. Glick, "Defying the Enlightenment: Jewish Ethnicity and Ethnic Circumcision," in *Genital Cutting: Protecting Children from Medical, Cultural, and Religious Infringements* (New York: Springer, 2013), 285-96; R.A. Shweder, "Shouting at the Hebrews: Imperial Liberalism versus Liberal Pluralism and the Practice of Male Circumcision," *Law, Culture and the Humanities* 5, no. 2 (2009): 247-65.

45. F.M. Hodges, "A Short History of the Institutionalization of Involuntary Sexual Mutilation in the United States," in *Sexual Mutilations* (New York: Springer, 1997), 17-40; D.L. Gollaher, *Circumcision: A History of the World's Most Controversial Surgery* (New York: Basic Books, 2000); D.L. Gollaher, "From Ritual to Science: The Medical Transformation of Circumcision in America," *Journal of Social History* 28, no. 1 (1994): 5-36; Waldeck, "Using Male Circumcision to Understand Social Norms as Multipliers," see note 2 above.

46. D.M. Kahan, "Cultural Cognition as a Conception

of the Cultural Theory of Risk,” in *Handbook of Risk Theory*, ed. S. Roeser et al. (Dordrecht: Springer Netherlands, 2012), 725-59, 728.

47. M. Douglas, *Risk Acceptability According to the Social Sciences* (New York: Russel Sage, 1985), 60.

48. M. Douglas and A.B. Wildavsky, *Risk and Culture: An Essay on the Selection of Technical and Environmental Dangers* (Berkeley, Calif.: University of California Press, 1982), 8, 85.

49. Waldeck, “Using Male Circumcision to Understand Social Norms as Multipliers,” see note 2 above.

50. For a detailed explanation of the dimensions along which the two procedures are analogous, see B.D. Earp, “Female Genital Mutilation and Male Circumcision: Toward an Autonomy-Based Ethical Framework,” *Medicolegal and Bioethics* 5, no. 1 (2015): 89-104. See also, B.D. Earp, “Does Female Genital Mutilation Have Health Benefits? The Problem with Medicalizing Morality,” *Quillette Magazine*, 15 August 2017.

51. For an in-depth discussion, see B.D. Earp, “Between Moral Relativism and Moral Hypocrisy: Reframing the Debate on ‘FGM,’” *Kennedy Institute of Ethics Journal* 26, no. 2 (2016): 105-44.

52. WHO, “Eliminating Female Genital Mutilation: An Interagency Statement,” 2008, apps.who.int/iris/handle/10665/43839.

53. D.S. Davis, “Male and Female Genital Alteration: A Collision Course with the Law,” *Health Matrix* 11 (2001): 487-570; K.S. Arora and A.J. Jacobs, “Female Genital Alteration: A Compromise Solution,” *Journal of Medical Ethics* 42, no. 3 (2016): 148-54; A. Shahvisi, “Why UK Doctors Should Be Troubled by Female Genital Mutilation Legislation,” *Clinical Ethics* 12, no. 2 (2016): 102-8; A.K. Rashid, S.S. Patil, and A.S. Valimalar, “The Practice of Female Genital Mutilation among the Rural Malays in North Malaysia,” *Internet Journal of Third World Medicine* 9, no. 1 (2010): 1-8; S. Taha, “A Tiny Cut: Female Circumcision in South East Asia,” *Islamic Monthly*, 12 March 2013; R. Steinfeld and B.D. Earp, “How Different Are Female, Male and Intersex Genital Cutting?” *Conversation*, 15 May 2017, <http://theconversation.com/how-different-are-female-male-and-intersex-genital-cutting-77569>.

54. AAP, “Cultural Bias and Circumcision,” see note 34 above, p. 803.

55. AAP, “Male Circumcision (Technical Report),” e759, see note 1 above: “. . . there are social, cultural, religious, and familial benefits and harms to be considered as well. It is reasonable to take these nonmedical benefits and harms for an individual into consideration when making a decision about circumcision.”

56. BMA, “The Law and Ethics of Male Circumcision: Guidance for Doctors,” *Journal of Medical Ethics* 30, no. 3 (2004): 259-63, 261.

57. *Ibid.*

58. Earp, “Female Genital Mutilation and Male Circumcision,” see note 50 above.

59. In this regard, the female genitalia are, if anything, relatively more hospitable to bacteria, yeasts, and other potential sources of infection or disease, than are the male

genitalia due to the presence of the foreskin. E.J. Dielubanza and A.J. Schaeffer, “Urinary Tract Infections in Women,” *Medical Clinics of North America* 95, no. 1 (2011): 27-41. However, we expect that few people in Western medicine would be tempted to leverage this observation into a research program looking at the prophylactic health benefits of removing folds of tissue from the pediatric vulva.

60. A.F. Chung, J.M. Woodruff, and J.L. Lewis, Jr. “Malignant Melanoma of the Vulva: A Report of 44 Cases,” *Obstetrics & Gynecology* 45, no. 6 (1975): 638-46.

61. Thus, is conceivable that removing one testicle from each male newborn would reduce his risk of developing testicular cancer later in life without necessarily impairing normal development or fertility. It would also likely reduce the population-level incidence of testicular cancer and associated healthcare costs. Similarly, removing one breast bud from each infant girl would conceivably reduce her risk of developing breast cancer later in life—and so on. Again, however, few would see these possibilities as supporting a valid argument in favor of prophylactic testicle/breast bud removal from infant boys or girls.

62. Frisch and Earp, “Circumcision of Male Infants and Children as a Public Health Measure in Developed Countries,” see note 10 above; E. Ungar-Sargon, “On the Impermissibility of Infant Male Circumcision: A Response to Mazor (2013),” *Journal of Medical Ethics* 41, no. 2 (2015): 186-90.

63. The one exception to this may be in cases of recurrent, pathologic phimosis due to balanitis xerotica obliterans (lichen sclerosis et atrophicus), which is rare: A.M.K. Rickwood, “Medical Indications for Circumcision,” *BJU International* 83, no. S1 (1999): 45-51. Most cases of true phimosis can be treated in less invasive ways than circumcision, such as by the application of a steroid cream: A. Orsola et al., “Conservative Treatment of Phimosis in Children Using a Topical Steroid,” *Urology* 56, no. 2 (2000): 307-10.

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65. B.D. Earp, “In Defence of Genital Autonomy for Children,” *Journal of Medical Ethics* 42, no. 3 (2016): 158-63.

66. S. Holm, “Irreversible Bodily Interventions in Children,” *Journal of Medical Ethics* 30, no. 3 (2004): 237.

67. J. R. Taylor, A.P. Lockwood, and A.J. Taylor, “The Prepuce: Specialized Mucosa of the Penis and Its Loss to Circumcision,” *British Journal of Urology* 77, no. 2 (1996): 291-5.

68. P. Werker, A. Terng, and M. Kon, "The Prepuce Free Flap: Dissection Feasibility Study and Clinical Application of a Super-Thin New Flap," *Plastic & Reconstructive Surgery* 102, no. 4 (1998): 1075-82; G. Kigozi et al., "Foreskin Surface Area and HIV Acquisition in Rakai, Uganda (Size Matters)," *AIDS* 23, no. 16 (2009): 2209-13.

69. J.A. Bossio, C. Pukall, and S. Steele, "Examining Penile Sensitivity in Neonatally Circumcised and Intact Men Using Quantitative Sensory Testing," *Journal of Urology* 195, no. 6 (June 2016): 1848-53; M.. Sorrells et al., "Fine-Touch Pressure Thresholds in the Adult Penis," *BJU International* 99, no. 4 (April 2007): 864-69; Earp, "Infant Circumcision and Adult Penile Sensitivity," see note 15 above.

70. D. Harrison, "Rethinking Circumcision and Sexuality in the United States," *Sexualities* 5, no. 3 (2002): 300-16; Earp, "Sex and Circumcision," see note 15 above.

71. Freedman, "The Circumcision Debate," see note 18 above, p. e20160594.

72. T. Merwin, "Fleshing out Change on Circumcision," *Jewish Week*, 9 September 2012, <http://jewishweek.timesofisrael.com/fleshing-out-change-on-circumcision/>.

73. Kahan, "Ideology, Motivated Reasoning, and Cognitive Reflection," see note 22 above, p. 408.

74. Ibid.

75. Koehler, "The Influence of Prior Beliefs on Scientific Judgments of Evidence Quality," see note 22 above, p. 28.

76. Ibid., 39.

77. The emphasis is on "in principle." It is not clear whether Freedman's statement from the interview, despite superficial appearances, has any direct relevance for the debate concerning potential bias among the AAP Task Force. As noted, it is possible that a commitment to circumcision on religious grounds could incline someone, whether consciously or unconsciously, to give relatively more weight to evidence suggesting that the procedure is medically beneficial. However, (a) the existence of such an inclination cannot simply be inferred from a single case, and (b) even if it could be inferred, this would not entail a particular policy conclusion.

78. A.J. Muller, "To Cut or Not to Cut? Personal Factors Influence Primary Care Physicians' Position on Elective Newborn Circumcision," *Journal of Men's Health* 7, no. 3 (2010): 227-32, 227.

79. Z. Kunda, "The Case for Motivated Reasoning," *Psychological Bulletin* 108, no. 3 (1990): 480-98.

80. An alternative explanation reverses causation. This explanation says that a doctor's dispassionate reading of the medical literature causes him to make a decision about the risk/benefit ratio of newborn circumcision, and this decision, in turn, is what causes him to circumcise (or not circumcise) his own son. This could very well explain, at least in principle, the observed association between those two variables. However, it could not explain the other observed association, namely the one between one's own circumcision status and one's evaluation of the literature. At least, it could not explain this association if one was circumcised in infancy or early

childhood, as most of the doctors in this survey presumably were. This is because reverse causation in such a case would not be possible (one cannot retroactively circumcise oneself in infancy based on one's current, dispassionate reading of the medical literature).

81. L. Festinger, *A Theory of Cognitive Dissonance* (Stanford, Calif.: Stanford University Press, 1962); E. Harmon-Jones and C. Harmon-Jones, "Cognitive Dissonance Theory after 50 Years of Development," *Zeitschrift Für Sozialpsychologie* 38, no. 1 (2007): 7-16.

82. Waldeck, "Using Male Circumcision to Understand Social Norms as Multipliers," see note 2 above, p. 495.

83. We are reluctant to speculate about the circumcision statuses of the male AAP Task Force members or their European counterparts. However, if one considers the very high rate of neonatal circumcision in the United States until recently, and the very low rate of circumcision in Europe both historically and presently, the possibility of greater personal bias (in the sense just outlined) among the former cannot be discounted entirely. A related consideration can be illustrated by way of an analogy. Imagine a committee charged with preparing a technical report on the benefits and risks of labiaplasty for adolescent girls who have been diagnosed with "labial hypertrophy" (long labia). Now imagine an early draft of this report that does not include a detailed description of the anatomy and functions of the labia minora, that downplays the limitations of studies purporting to show that labiaplasty poses only a trivial risk to women's sexual enjoyment (or fails to mention such limitations altogether), and that implicitly assigns the female genital labia themselves a value of "zero" in its benefit-risk analysis (see table 1). It is not unreasonable to think that a female committee member with surgically unmodified genitalia, compared to one whose labia were removed in childhood, or who never had labia due to being male, would be significantly more likely to notice such oversights and propose that they be corrected before final publication. This is another sense, then, in which personal experience may factor into policy discussions.

84. AAP, "Cultural Bias and Circumcision," see note 34 above, p. 801.

85. AAP, "Male Circumcision (Technical Report)," see note 1 above, p. e758.

86. Morris, Bailis, and Wiswell, "Circumcision Rates in the United States," see note 11 above.

87. Freedman, "The Circumcision Debate," see note 18 above.

88. R. Merkel and H. Putzke, "After Cologne: Male Circumcision and the Law. Parental Right, Religious Liberty or Criminal Assault?" *Journal of Medical Ethics* 39, no. 7 (2013): 444-9.

89. B.D. Earp, "Mental Shortcuts," *Hastings Center Report* 46, no. 2 (2016): inside front cover; B.D. Earp and D. Trafimow, "Replication, Falsification, and the Crisis of Confidence in Social Psychology," *Frontiers in Psychology* 6, no. 621 (2015): 1-11.

90. See B.D. Earp, "'Legitimate Rape,' Moral Coherence, and Degrees of Sexual Harm," *Think* 14, no. 41

(2015): 9-20; see also E. Vogelstein, "Professional Hubris and Its Consequences: Why Organizations of Health-Care Professions Should Not Adopt Ethically Controversial Positions," *Bioethics* 30, no. 4 (2016): 234-43. Ironically given the arguments in the present article, Vogelstein explicitly exempts the AAP 2012 circumcision policy from his proposed prohibition on healthcare organizations adopting controversial positions. See R.S. Van Howe, "Response to Vogelstein: How the 2012 AAP Task Force on Circumcision Went Wrong," *Bioethics*, in press.

91. R. Collier, "Ugly, Messy and Nasty Debate Surrounds Circumcision," *Canadian Medical Association Journal* 184, no. 1 (2012): E25-6; B.D. Earp, "Addressing Polarisation in Science," *Journal of Medical Ethics* 41, no. 9 (2015): 782-4.

92. Van Howe, "The American Academy of Pediatrics and Female Genital Cutting," see note 19 above.

93. 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.

94. M. Benatar and D. Benatar, "Between Prophylaxis and Child Abuse: The Ethics of Neonatal Male Circumcision," *American Journal of Bioethics* 3, no. 2 (2003): 35-48; J. Mazor, "The Child's Interests and the Case for the Permissibility of Male Infant Circumcision," *Journal of Medical Ethics* 39, no. 7 (2013): 421-28; J. Savulescu, "Male Circumcision and the Enhancement Debate: Harm Reduction, Not Prohibition," *Journal of Medical Ethics* 39, no. 7 (2013): 416-7.

95. M. Fox and M. Thomson, "Short Changed? The Law and Ethics of Male Circumcision," in *Children's Health and Children's Rights* (Leiden, the Netherlands: Brill, 2006), 161-82; D.L. DeLaet, "Framing Male Circumcision as a Human Rights Issue? Contributions to the Debate over the Universality of Human Rights," *Journal of Human Rights* 8, no. 4 (2009): 405-26; D.L. DeLaet, "Genital Autonomy, Children's Rights, and Competing Rights Claims in International Human Rights Law," *International Journal of Children's Rights* 20, no. 4 (2012): 554-83; G.J. Boyle et al., "Circumcision of Healthy Boys: Criminal Assault?" *Journal of Law and Medicine* 7, no. 1 (2000): 301-10; R. Merkel and H. Putzke, "After Cologne: Male Circumcision and the Law," see note 88 above; K.-K. Ford, "'First, Do No Harm': The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants," *Yale Law & Policy Review* 19, no. 2 (2001): 469-88; B.D. Earp, J. Hendry, and M. Thomson, "Reason and Paradox in Medical and Family Law: Shaping Children's Bodies," *Medical Law Review*, in press; B.D. Earp and R. Steinfield, "Gender and Genital Cutting: A New Paradigm," in *Gifted Women, Fragile Men*, ed. T. G. Barbat, Euromind Monographs 2 (Brussels, Belgium: ALDE Group-EU Parliament, 2017); J.S. Svoboda, P.W. Adler, and R.S. Van Howe, "Circumcision Is Unethical and Unlawful," *Journal of Law, Medicine & Ethics* 44, no. 2 (2016): 263-82; J.S. Svoboda, "Promoting Genital Autonomy by Exploring Commonalities between Male, Female, Intersex, and Cosmetic Female Genital Cutting," *Global Discourse* 3, no. 2 (2013): 237-55; M. Dustin, "Female Genital Mutilation/

Cutting in the UK: Challenging the Inconsistencies," *European Journal of Women's Studies* 17, no. 1 (2010): 7-23.

96. J.S. Svoboda and R.S. Van Howe, "Out of Step: Fatal Flaws in the Latest AAP Policy Report on Neonatal Circumcision," *Journal of Medical Ethics* 39, no. 7 (2013): 434-4. 435.

97. AAP, "Male Circumcision (Technical Report)," see note 1 above, p. e759.

98. *Ibid.*

99. For a closely related view concerning female children's genitals specifically, see A. Rahman and N. Toubia, *Female Genital Mutilation: A Practical Guide to Worldwide Laws & Policies* (London and New York: Zed Books, 2000). These authors state, "The cutting of healthy genital organs for non-medical reasons is at its essence a basic violation of girls' and women's right to physical integrity. This is true regardless of the degree of cutting or the extent of the complications that may or may not ensue."

100. J. Chegwiddden, "Response: Tasmanian Law Reform Institute Issues Paper No. 14: Non-Therapeutic Male Circumcision," 2009, http://www.utas.edu.au/_data/assets/pdf_file/0003/28370/CircumcisionIssuesPaperA4toPrint.pdf.

101. *Ibid.*

102. Davis, "Male and Female Genital Alteration," see note 53 above.

103. D.M. Shaw, "Beyond Conflicts of Interest: Disclosing Medical Biases," *Journal of the American Medical Association* 312, no. 7 (2014): 697-8. This is not to say that financial conflicts of interest are not relevant. As a reviewer for this paper points out, the fact that circumcision generates sometimes substantial incomes for American doctors in the context of a for-profit medical system should not be discounted. This monetary aspect plausibly does play a role in perpetuating circumcision in the United States. As Christopher Price states, "Circumcision is a very complex issue [about which it has been said that] 'Mothers demand it, doctors profit by it, and babies cannot complain about it.' It is estimated that, with more than one million circumcisions a year at a cost on the order of \$200 each, doctors in the United States earn in excess of \$200 million *per annum*, from circumcisions. Such a major financial incentive to continue routine neonatal circumcision helps cloud the legal and ethical issues inherent in this activity." C. Price, "Male Non-Therapeutic Circumcision: Legal and Ethical Issues," in *Male and Female Circumcision* (New York: Springer US, 1999), 425-54. With respect to the AAP Task Force in particular, we note that, while no financial (or other) conflicts of interest were disclosed in the original AAP documents, a financial conflict of interest was in fact included in the AAP response to the European critics, as follows: "FINANCIAL DISCLOSURE: Dr. Carlo is a Director of Mednax; the other authors have indicated they have no financial relationships relevant to this article to disclose." This disclosure is hard to interpret, as no details are given as to the nature of the financial conflict of interest; it is also of concern that the conflict—whatever it is—was not mentioned in the original policy statement or technical report. AAP, "Cultural

Bias and Circumcision,” see note 34 above, p. 801.

104. Shaw has argued from this premise that committee members should be required to disclose, as a potential conflict of interest, whether they are circumcised or have circumcised their son (Shaw, “Beyond Conflicts of Interest,” see note 103 above). However, we will not pursue that argument here.

105. R.S. Van Howe, “The American Academy of Pediatrics and Female Genital Cutting,” see note 19 above.

EVALUATION

1. The following objectives were met:
 - a. Evaluate the charge of cultural bias, focusing on possible sources of subjective judgments that could play into assessment of benefit versus risk (check one):
 - Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
 - b. Discuss ongoing disagreements about the ethical status of nontherapeutic infant male circumcision (check one):
 - Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
 - c. Draw general lessons about the problem of cultural bias in medicine (check one):
 - Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
2. This activity was free of commercial bias (check one):
 - Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree
3. This activity was a valuable use of my time (check one):
 - Strongly agree
 - Agree
 - Neutral
 - Disagree
 - Strongly disagree

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Partial Survivors: The Brokenness of Intact Survival

Paul C. Mann

ABSTRACT

Intact survival is a medical phrase that denotes a patient's survival following critical care hospitalization that does not include residual neurologic impairments. First proposed as the ideal neurodevelopmental outcome for prematurely born infants in the late 1950s, it remains a commonly cited neurologic outcome goal in the medical literature for patients of all ages. A clinical focus on intact survival, however, may have unintended consequences when neurologic outcomes are uncertain, contributing to a fallacious understanding of neurodevelopmental impairments and detrimentally impacting families whose children suffer neurologic disability.

William A. Silverman, MD, an influential and distinguished pioneer in the field of neonatology, left behind an enduring legacy at his death, with innumerable landmark contributions to medical science.¹ For these many notable accomplishments, however, one lasting influence Silverman has had on medical parlance and perspectives of neurologic outcome is infrequently, if at all, attributed to him.

In October of 1958, Silverman was honored by the Society for Pediatric Research with the E. Mead Johnson Award and invited to speak at the annual meeting of the American Academy of Pediatrics. His

address focused principally upon research he had been conducting into the impacts of variable incubator settings on survival for infants who had been born prematurely.² The talk took a more philosophical turn towards the end, however, as Silverman pressed the importance of targeting a goal beyond survival in determining optimal environments to care for premature infants. His audience was asked to consider the substantive rates of brain injury in survivors of neonatal intensive care and to direct their efforts towards a more ideal clinical outcome that he coined "intact survival." While improving neurodevelopmental outcomes for premature infants was the implicit objective of this proposal, no specific targets were offered by Silverman by which to judge which infants survived their intensive care ordeal "intact." Silverman did disclose, however, his creative inspiration for these formative ideas about quality of survival was an entomological study outlining ideal incubator temperatures for rearing European brown-tail moths.³

The speech seems to have profoundly influenced the perinatal community. Within 10 years, the goal of intact survival had become so entrenched within its collective consciousness that it received substantial attention when multidisciplinary experts convened in 1969 at the National Institute of Child Health and Human Development to discuss key issues in infant mortality. The published report of that conference mentions Silverman's ideal of intact sur-

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vival more than 15 times.⁴ Conference participants expressed their desire to shift the focus of neonatal medical care from a reduction in infant mortality towards ensuring that all survivors became “whole, healthy individuals.” A good deal of difficulty, though, was confessed with defining what exactly constituted intact survival. “Do we use IQ levels? Motor development? Where do we draw the line between someone who will be a useful member of so-

cal illness without long-term neurodevelopmental impairments.¹¹

The ongoing use of intact survival to describe the outcome of survival without neurologic disability, however, is problematic for patients of all ages. While the motivation for clinicians to use this terminology is probably multifactorial, fears of a poor future quality of life following neurologic injury are likely a central concern, with a desire to avoid bur-

Conference participants expressed their desire to shift the focus of neonatal medical care from a reduction in infant mortality towards ensuring that all survivors became “whole, healthy individuals.”

ciety and someone who will not?” wondered those participating.

These struggles were echoed in the 1972 *Report of the President’s Committee on Mental Retardation*, which both championed and cautioned against embracing modern technology to save the lives of premature infants and high-risk infants born at full term.⁵ The report noted that while a large percentage of babies treated with intensive care approaches may survive, many would “emerge with serious mental defects.” Deeply concerned with such outcomes, one physician affirmed that, in caring for these babies, “the goal is not survival, it is intact survival.”

The phrase intact survival remains prevalent throughout medical literature for neonates, children, and adults to help qualitatively label desirable and undesirable neurologic outcomes for emergency and critical care interventions. Descriptive characterizations of what it means to be neurologically “intact” vary greatly, though, if they are defined at all. Some studies describe intact survival as survival without serious morbidity⁶ or survival with an absence of poor prognostic factors such as intraventricular hemorrhage.⁷ Others studies denote intact survival as the avoiding specific sequelae like cerebral palsy and blindness⁸ or maintaining the ability to carry out daily living activities independently.⁹ In general, adolescent and adult patients survive life-threatening events such as traumatic brain injury or cardiac arrest “intact” if they regain their pre-state baseline without significant residual neurologic deficits.¹⁰ For neonates and younger children, surviving hospitalization “intact” necessitates recovery from a criti-

dening patients, caregivers, and society at large with significant neurologic disability as a clinical outcome. Quality of life concerns and the possibility of future neurodevelopmental impairments are commonly cited reasons for withdrawing life supportive care in children, especially neonates.¹² Quality of life estimations, though, are decidedly personal, value-laden, and subject to significant biases.¹³ Troublingly, health professionals have been reported to have misinformed stereotypes and pejorative opinions of individuals with neurologic disability, including reduced valuations of their lives,¹⁴ which could prejudice judgments of what constitutes an “intact” person.

Evaluating neurologic injuries through the lens of intact survival may also encourage a fallacious binary paradigm in which a predicted neurodevelopmental outcome becomes a singular entity that the clinician judges to be either “good” or “bad.” That is a harmful construct that is misleading for families, as it ignores the intricate complexity and fallibility of neurologic prognostication.¹⁵ Following neurologic injury, children frequently develop variable degrees of long-term impairment in different areas of neurodevelopment (for example, mobility may be much more impaired than cognitive functioning).¹⁶ Neurodevelopmental outcomes for two patients with similar injury can be very different given the significant influences of a multitude of mitigating factors such as neuroplasticity and socioeconomic inequalities (for example, maternal education level, access to rehabilitative and special education services).¹⁷ Some children will have outcomes that are much better than initially prognosti-

cated,¹⁸ others much worse. To best aid clinical decision making in these contexts, especially as it relates to conversations regarding limitations of life-supportive care, families must comprehensively understand the distinctive types of possible functional impairments for their child and receive specific descriptions of how daily living may be altered. Parents can then discern for themselves how those potential outcomes might affect their family, defining “good” and “bad” on their own terms.¹⁹

It is imperative to critically appraise the ramifications of clinical concerns for intact survival and neurologic disability on patients’ outcomes. The impacts of negative views of disability on medical decision making are understudied, but likely contribute to worrisome patterns of paternalism when patients’ neurologic outcomes are uncertain. The many forms of such paternalism include: counseling (and sometimes pressuring) families to discontinue life-sustaining interventions early in hospitalizations that have been complicated by neurologic injuries, when spontaneous respiratory functioning is unlikely if the patient is extubated from mechanical ventilation (the so-called “window of opportunity”); incessantly communicating poor neurologic prognoses to families (the underlying supposition being they must not “get it” or otherwise would be in agreement with the medical team to stop “aggressive” interventions); presuming a family will be unable to accommodate neurologic disability in their loved one; and conflating functional neurologic impairments into deterministic socioeconomic outcomes with certain deleterious impacts such as social isolation, impoverishment, and marital collapse.²⁰

Initial communication from clinicians regarding potential neurologic impairments for a child can have lasting consequences on how a family copes with disability. A study by Graungaard and Skov reports that parents expected clinicians to appreciate the emotional impact of their words in these contexts, and expected clinicians to empathetically communicate worrisome neurologic prognoses.²¹ Instead, many parents disclosed a troublesome disconnect between themselves and their medical careproviders descriptive judgments of their child’s potential—namely that clinicians define the child in terms of disability, instead of possibility.²² These discordant perceptions can lead to families distrust the intentions of the medical team, adopting a defensive posture to “protect” their loved one.²³

Disparaging judgments of neurologic outcomes also can have detrimental impacts on disabled survivors, precluding their wishes to be seen as the

persons they once were.²⁴ Children recovering from neurologic injury describe being keenly aware of how others, including healthcare providers, redefine their quality of life, and that they have substantial difficulties adjusting to the attitudinal limitations placed on their future opportunities.²⁵ Notably, such negative attitudes about quality of life with a neurologic disability ignore the enriching aspects of disability that many survivors and families experience.²⁶

Descriptions of neurologic disability in critical care survivors that focus principally upon which patients are likely to survive “intact” are of limited clinical value. Linking the inherent worth of patients to their neurologic attributes and cognitive capabilities ignores more relational aspects of their personhood and risks a wide range of undesirable clinical consequences, such as careproviders spending less time with their disabled patients and not advocating adequately for their rights.²⁷ It is imperative, instead, that we more compassionately discuss potential neurologic injuries for our patients in terms of specific impairments, counseling broadly enough to include the range of possible outcomes and patiently enough for families to process the implications.

On a hopeful note, there is evidence that the phrase intact survival is beginning to fall out of favor, especially with neonatologists.²⁸ Historically, however, abolishing controversial language as it relates to disability (for example, “defective,” “mongoloid,” “retarded”), has not significantly lessened the challenges that individuals and families of individuals with developmental disabilities face in obtaining equitable, quality healthcare.²⁹ New models of care are needed for families who choose to accommodate significant disability in their loved ones, focused on comprehensive support throughout the various transitions in the patients’ neurodevelopment.³⁰ In that spirit, perhaps it is time for the pediatric community to champion a goal of a different type of intact survival, keeping families intact whose children have suffered neurologic injuries.

NOTES

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If Truth Be Told: Paternal Nondisclosure in Neonatal Herpes Simplex Virus Infections

William Sveen, Meera Sury, and Jennifer Needle

ABSTRACT

An infant is treated for a suspected neonatal herpes simplex virus (HSV) infection. The mother requests that the father not be informed of his child's diagnosis or treatment, as the father is not aware of the mother's possible HSV infection or her extra-relational sexual encounter. The obligation to inform the father of his child's treatment is in conflict with the obligation to protect the confidentiality of the mother's sexual history. While outright deception of the father is unethical, options exist to limit disclosure of the mother's sexual history, since those details are not directly relevant to the father's ability to make informed medical decisions about his child's care. The careprovider should inform the mother of the complex and recurrent nature of HSV infections and empower her to select an option that will inform the father of the concern for HSV infection and the need for treatment in a manner that she feels will best protect her confidentiality. Objections to this method are evaluated and countered.

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CASE

A mother brings her 10-day-old male baby to the emergency department with a fever. The child is irritable, but without a clear source of infection. He was born full term via vaginal delivery with no documented complications during the pregnancy, delivery, or newborn period. Through further questioning, the mother describes a history of genital lesions in the second trimester consistent with herpes simplex virus (HSV) and is unsure if she has had similar lesions in the past. She was sexually active with the father of the infant throughout the pregnancy and had an extra-relational, unprotected sexual encounter during the pregnancy. The parents are not married, but cohabit and parent the child together as legal guardians.

Due to concerns for serious viral or bacterial infection, the patient is admitted to the hospital, a full workup is performed, and broad-spectrum antimicrobial therapy is initiated, including treatment for HSV. The mother requests that the careprovider not tell the infant's father about the treatment for HSV, as he does not know about her extra-relational sexual encounter, and she is concerned that this knowledge will damage their relationship.

HSV-1 and -2 are common viruses that spread between individuals by direct contact, often through

oral or genital contact during kissing or sexual intercourse. Mother-to-child transmission during or shortly after birth is responsible for neonatal HSV. Neonatal HSV can cause a spectrum of disease from mucocutaneous involvement of the skin, eyes, and mouth; central nervous system involvement; or dissemination to multiple organs. Without prompt treatment, neonatal HSV has a high rate of mortality and disability. HSV is difficult to diagnose clinically, as a child may not have typical vesicular lesions, and the mother may not recall any symptomatic infections during pregnancy, requiring viral cultures and a PCR (polymerase chain reaction) assay to confirm diagnosis.¹

TRUTH-TELLING IN PEDIATRICS

The importance of truth-telling has changed throughout the history of medicine. In the 19th century, medicine was highly paternalistic. Doctors believed it was acceptable to withhold information or lie outright to “protect” their patients, at least in part due to a common belief that giving a poor prognosis was harmful to patients.² With the evolution of medicine to more highly value patients’ autonomy and patients’ preferences to hear the truth, regulations requiring informed consent for research and treatment have also evolved. As diagnostic information provides more reliable data, truth-telling has become fundamental to medical practice in the United States.³ Today, the argument for truth-telling is rooted in the principle of respect for patients’ autonomy, because patients’ knowledge of their condition is a prerequisite to their being able to make informed decisions regarding their health.⁴

The application of truth-telling in pediatrics is less clear because the principle of respect for patients’ autonomy does not directly apply to children.⁵ In pediatrics, careproviders’ primary moral obligation remains with the patient, but the primary legal obligation is with the patient’s parents or legal guardians. Additionally, a child’s ability to process information depends on her or his development. Infants are incapable of understanding any information, young children may have minimal understanding, and adolescents may process information similarly to adults. According to the American Academy of Pediatrics, communication with families should be family-centered, frequent, clear, and honest, but hopeful whenever possible.⁶

The application of these principles in specific situations may be controversial, in part because the interests and rights of parents and children may be in conflict. For example, the pediatric ethics litera-

ture discusses the nuances of when to withhold information about a grave diagnosis from a child at the request of parents,⁷ or when to withhold information about an adolescent’s social behaviors from her or his parents.⁸ However, the literature regarding nondisclosure of medical information from a child’s parent at the request of another parent is sparse.

ETHICAL OPTIONS

Any level of deception of parents that compromise the care of their child is unethical. In this case, the child will receive the needed treatment regardless of the father’s knowledge of the child’s diagnosis or treatment. The mother’s desire to keep her sexual health history confidential and the father’s legal right to access his child’s health information represent a potential ethical conflict for the care-provider. The ethical question centers around whether the confidentiality of the mother outweighs the right of the father to be informed about his child’s medical care.

The father has a legal and a moral right to access his son’s medical information. Specifically, he should be informed of the treatments his son is receiving, the pending tests, the diagnoses being considered, and possible prognosis. Furthermore, the father should be included in any decisions to be made about the care of his child.

The mother has a right to keep her personal sexual history confidential. Revealing her extra-relational sexual encounter may have a wide range of effects on the relationship she has with the child’s father. The environment in which the child grows up may be negatively affected. Weighing the risks and benefits of disclosing the sexual encounter to the father is not the physician’s role. Aside from the obvious stress that disclosure may place on the relationship, the stigmatization of HSV makes disclosure particularly challenging, including the risks of psychological and social trauma.⁹ In addition, the mother’s extra-relational encounter may have further cultural and religious implications. These could be severe, including abandonment by her family and exclusion from her community.

The benefit to the mother of nondisclosure may outweigh the possible harm to the father. Based on legal obligations, generally held ethical standards, and the consideration of the patient and family members, an outright lie to the father about the care of his child is ethically unjustifiable.¹⁰ The “reasonable patient” principle considers what most reasonable patients would want. Applying this principle

to pediatrics, one can expect that most fathers would want to know the diagnoses and treatments concerning their child.¹¹

Given the complexity and recurrent nature of HSV infection, disclosing medical information to the father and protecting the mother's confidentiality are not mutually exclusive. The mother's HSV infection could be from a relationship that preceded the current relationship with the father, and although a secondary recurrence of an infection is much less likely

the test is positive, of telling the father about the diagnosis and that the child is being treated.

OBJECTIONS CONSIDERED

The careprovider may not actively deceive the father to protect the mother by citing therapeutic privilege. Therapeutic privilege is a controversial concept that is used to justify deceiving a patient for the benefit of that patient.¹⁴ For example, a care-

One option would be to discuss these nuances with the mother, and develop a plan to inform the father of the child's need for treatment while protecting the mother's confidentiality to the highest degree possible. Another option would be to place the responsibility for informing the father with the mother.

to be transmitted to an infant, this is possible.¹² Additionally, it is entirely possible that the HSV infection was transmitted from the father to the mother, and that he acquired it either from a prior relationship or a concurrent extra-relational encounter. One option would be to discuss these nuances with the mother, and develop a plan to inform the father regarding the child's need for treatment while protecting the mother's confidentiality to the highest degree possible.

Another option would be to place the responsibility for informing the father with the mother. This would allow her to inform him on her own terms. The mother should be warned that if the father asks a direct medical question, it will be answered truthfully. A third option would be to give the father general information about the prevalence and severity of neonatal HSV without stating that it is sexually transmitted. This would leave open the possibility that if the father asks a direct medical question, it will be answered truthfully.

A more controversial option would be to wait until the PCR assay returns, which typically is in 24 to 48 hours, before telling the father about the HSV infection. If the assay is negative, which is the most likely result, since the child has no lesions, acyclovir would be discontinued.¹³ This approach would be morally questionable because the father would not be informed about the multiple doses of antiviral medication and related testing, and runs the risk, if

provider could claim therapeutic privilege to mislead a child who has end-stage metastatic cancer to convince her that she is not dying, because the knowledge of her condition may cause her serious psychological harm. Therapeutic privilege cannot be used in this case for two reasons. First, it is not the patient who is being deceived. Second, it is not the patient who receive primary benefit from the deception, but the mother. Deceiving the father may protect the mother, which may benefit the child in some situations by keeping the family intact or protecting the mother from abuse. But the likelihood of keeping the family together through deception is not easily determined by the careprovider, and concerns about a possibly abusive situation warrants discussion regarding the involvement of child protective services.

A second objection to deceiving the father is that it is immoral to not provide him with all of the medical facts known to the mother. On the other hand, the moral obligation to disclose information is tied to the relevance of the information;¹⁵ disclosing all medical information is impractical and often impossible. A careprovider could spend hours discussing the epidemiology, pathophysiology, and management of HSV infection. Instead, a reasonable careprovider will narrow the information presented to what is relevant to the family. In this case, the concern regarding neonatal HSV infection is relevant to the father's ability to make medical decisions for

his son, but the sexual history of his partner is not. While any attempt to deceive the father about his child's possible neonatal HSV infection is morally indefensible, specific information about the mother's sexual activity is not relevant to the child's care. Although withholding this information may appear to be deceptive, the benefits of withholding the mother's sexual history could outweigh the benefits of revealing that information to the father.

A third objection is that the father deserves to be informed of his risk of contracting HSV from the mother. This objection is problematic for multiple reasons. First, the mother does not have a confirmed HSV infection. Second, the child is the patient, not the father or the mother, and the careprovider's obligation is to the child. Third, a careprovider generally does not have a duty to inform an adult patient's sexual partners about their risk of contracting HSV from a patient, although the careprovider should encourage infected individuals to disclose their status to exposed partners.¹⁶

CONCLUSION

In this case, an obligation to inform the father about his son's medical care is in conflict with an obligation to keep the mother's sexual history private. This ethical dilemma appears to challenge the careprovider to choose between protecting the mother's confidentiality and involving the father in decision making for his son. The relevant medical information the father needs to make informed decisions about his son does not include information regarding an extra-relational sexual encounter his partner had during pregnancy. Given the complex and diverse clinical presentations and transmission of HSV, the careprovider should suggest multiple ways to inform the father of the concern for neonatal HSV, and empower the mother to select an option that she feels will best protect her confidentiality. While requiring additional attention and time to balance the interests of both parents, this approach ensures that the careprovider allows both parents to participate in the care of their child and does not force the careprovider to deceive the father or betray the mother.

PRIVACY

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

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“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 compo-

nents 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.

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 gastrostomy 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.

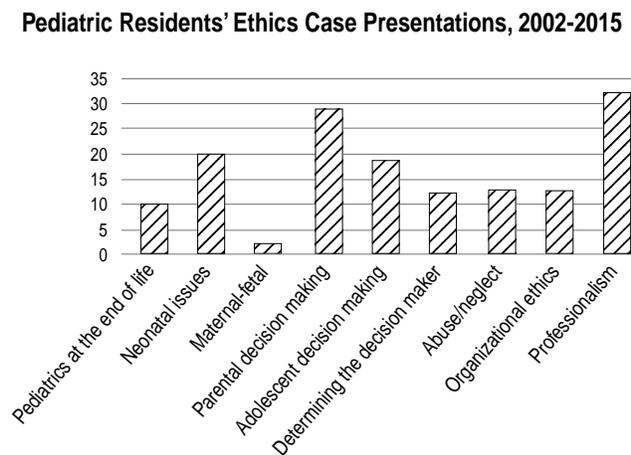


FIGURE 1.

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

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

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.

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,

S.H. without any consideration of the real-world options and how they would affect S.H.

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.

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The Ethical Implications of Bias in Counseling Parents of Children with Trisomy 13 and 18

Rebecca J. Benson, Laura A. Shinkunas, and Joy Salls

ABSTRACT

Many physicians continue to see serious chromosomal abnormalities as lethal or “incompatible with life.” A diagnosis of trisomy 13 or 18 is associated with a high risk of perinatal death, but children who survive the neonatal period may continue to live for several years. In sharing diagnoses with family members, physicians may convey their bias with family members. Shared decision making, using a model of patient-centered care, may help physicians to avoid conveying such bias.

INTRODUCTION

A generation ago there was implicit agreement among physicians that life-sustaining measures were

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Joy Salls is the mother of Cora, a child with trisomy 18.

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not indicated for a diagnosis of trisomy 13 or 18 due to the severity of the anomalies.¹ Recent studies show this viewpoint persists among physicians, despite several societal changes that have influenced the approach to counseling families of children with serious illness.² These changes include a shift from paternalism to an emphasis on shared decision making,³ changes in our ideas about treatment of people with disabilities,⁴ and an increase in social media that allows parents to connect with each other outside of the healthcare system.⁵ Despite these changes, most healthcare providers who encounter these serious chromosomal abnormalities are still likely to use terms such as “incompatible with life” or “lethal” as they think about how to describe the prognosis to the family. A diagnosis of trisomy 13 or 18 is associated with a high risk of perinatal death, with a median survival rate that is typically less than two weeks.⁶ However, children who survive the neonatal period may go on to live for several years. In a retrospective cohort study carried out over 21 years (1991-2012) in Canada, the one-year survival rate for children with trisomy 13 was 19.8 percent and 12.6 percent for children with trisomy 18.⁷ The 10-year survival rate for children with trisomy 13 was 12.9 percent and 9.8 percent for those with trisomy 18.⁸ A significant number of the children in this study underwent surgeries ranging from myringotomy (surgery in which an incision in the eardrum to reduce pressure behind it) to complex cardiac

repair, and had one-year survival rates of around 70 percent.⁹ In a multi-state study of survival in children with trisomy 13 or 18, preterm birth and major organ birth defects, such as omphalocele (a rare defect in which the intestine, liver, and other organs are located outside the abdominal wall) were found to be most predictive of death in the neonatal period.¹⁰ Finally, in a population-based analysis of mortality in children with trisomy 13 and 18, girls and African-Americans had a higher rate of survival.¹¹ Surviving children with these aneuploidies (chromosomal abnormalities) uniformly have cog-

in addition to what they are given by the medical team, especially via the internet and social media. Depending on what families choose to read and how they interpret the information, they could easily be exposed to material that is biased toward a more positive outlook. Families may be drawn toward stories of children who survived against the odds, and they may develop an understandable hope that their child will also outlive medical expectations. Janvier and colleagues surveyed 332 parents who were members of support groups for their children diagnosed with trisomy 13 or 18, with the purpose of

***Children with severe impairments can still be perceived
by their families and careproviders as having
an excellent quality of life.***

nitive and physical disabilities, although with significant heterogeneity throughout the population in terms of specific organ anomalies. One consistent feature is the severity of neurocognitive deficits. These studies report that treatment for children with trisomy 13 and 18 is not unequivocally futile in terms of survival.

Healthcare professionals need to consider future quality of life when they counsel a family about what they feel is in the best interest of the child. In a recent editorial, Lantos described treatment decisions for children with trisomy 13 and 18 as “in a stable gray zone” in bioethics.¹² The factors that contribute to this “gray zone” include a high mortality rate, severe neurocognitive deficits, and potential for high burden of treatment.¹³ For this reason, he suggests that parental values should drive decisions, with tolerance of variability in choices and outcomes.¹⁴ Lantos also highlights a traditional bias among healthcare professionals that children with trisomy 13 or 18 have a very poor quality of life.¹⁵ He reminds us that quality of life should not be equated with physical or neurological impairment.¹⁶ Parents report that their children with an aneuploidy are typically comfortable and experience the good things in life; they smile and laugh, and they bring joy and meaning to their families.¹⁷ Children with severe impairments can still be perceived by their families and careproviders as having an excellent quality of life.

It is important to note that families may also have bias. Many families now have access to information

describing the parents’ lived realities and points of view.¹⁸ Janvier and colleagues concluded that parents in support groups were often able to find positive accounts of children living with trisomy 13 and 18, which could then lead to differences of opinion between parents and healthcare providers about the appropriateness of medical interventions.¹⁹ Thus, families may tend to be biased toward thinking about the best case scenario and how the intervention will benefit their child. Healthcare professionals, on the other hand, tend to take a more utilitarian view toward decision making when the situation falls into the “stable gray zone,” balancing the benefits and risks of an intervention for the individual patient against the burden on the healthcare system in terms of the utilization of resources. This may bias healthcare professionals toward thinking about the most likely medical outcome, rather than the best case scenario.

Given the potential for bias and the bioethical gray zone of making treatment decisions, Haug and colleagues advocate for and describe a patient-centered care approach to counseling families, based on the recommendations made in 2001 by the Institute of Medicine (IOM).²⁰ These patient-centered concepts were established to define quality in healthcare delivery and include dignity and respect, information sharing, participation, and collaboration.²¹ The IOM recommendations list specific approaches that can help careproviders to facilitate decision making in an ethically sound manner that considers the well-being of all involved. Haug and

colleagues take the recommendations and specifically focus on counseling after a prenatal diagnosis, but the concepts included in these recommendations are applicable to treatment decisions throughout a child's life. We will discuss the application of these concepts in the setting of Cora and her family's experience, as told by her mother, Joy Salls, one of the authors.

DISCUSSION

The Salls Family's Experience

Cora was born at a small, rural hospital. My husband and I did not have a prenatal diagnosis and received her diagnosis of trisomy 18 when she was three days old. We have been fortunate to have support from pediatric palliative care as well as many other specialties to help us navigate our journey. Cora has had many struggles. She has had surgeries to open her eyelids, place a gastrostomy tube, and stabilize her gut; an appendectomy; cardiac repair; sutures on her eyelids; and surgery to release her tethered spinal cord. She had the most pain from teething, but is otherwise generally happy and interactive, which vouches for her quality of life, even through many difficult trials.

Cora is the light of our world and has an amazing bond with her little sister. Cora turned three in September 2016.

PATIENT-CENTERED CONCEPT NUMBER 1: DIGNITY AND RESPECT

The majority (98 percent) of parents of children with trisomy 13 or 18 who responded to a questionnaire about their experience felt that their family was strengthened and enriched by the birth of their child, regardless of their child's longevity.²² The same group of parents reported four reasons for continuing the pregnancy after receiving a prenatal diagnosis of trisomy 13 or 18: moral/religious beliefs or personal values (77 percent); child-centered reasons, such as the baby was already a loved member of the family (64 percent); patient-centered reasons such as wanting to get to know the baby even if time was limited (28 percent); and practical reasons, such as being unable to terminate the pregnancy (6 percent).²³ Thus, the majority of parents who participated in the study based their approach to decision making on moral or religious beliefs and their child's identity as their son or daughter, despite being given this life-changing diagnosis. This differs from the perspectives of many healthcare professionals, in which there is a tendency to focus on the diagnosis

and prognosis, rather than on individual dignity and the family's values.

Among other ways to support dignity and respect, Haug and colleagues advocate for assessing values, beliefs, and preferences throughout the continuum of care; supporting parents in making decisions that fit with their values; and creating opportunities for careproviders to listen to the healthcare experiences of patients.²⁴

The Salls Family's Experience

When Cora was six months old, she and I were invited to speak at Grand Rounds at Fletcher Allen Health Care in Vermont. It was an honor, as many of her doctors and specialists were in attendance. There were also many there whose only knowledge of trisomy 18 was that it meant an infant would not live very long. I know there are medical professionals who do not believe in providing a range of treatment options to parents of children with trisomy 18 because of this perception. When I spoke to this room of doctors, I told them, "Cora is perfect. She was perfect from the first breath she took, and will be perfect until the last breath she takes." I believe Cora had an impact on many that day, and hopefully, sharing her story changed their perception of how to work with a family who has a child with a trisomy diagnosis.

PATIENT-CENTERED CONCEPT NUMBER 2: INFORMATION SHARING

Parents who receive a prenatal diagnosis of trisomy 13 or 18 often report that they were given very directive counseling, based only on the diagnostic category of trisomy 13 or 18, without consideration for the specifics of their child's unique clinical status.²⁵ Families said that they found it most helpful when healthcare professionals gave balanced and personalized information, when their choices were respected, and when they were provided with support. The plan of care (comfort care, limited interventions, or full interventions) that parents chose was significantly associated with the child's anomalies. For example, if the child had neither cardiac defects nor holoprosencephaly—when the embryo's forebrain does not develop into two hemispheres—the parents were much more likely to choose full interventions than if the child had both conditions. The patient-centered care model recommends presenting accurate figures for survival and outcome that take into account the unique clinical features present, avoiding unmodified use of the terms "lethal," "fatal," or "incompatible with life," and to give

information about educational resources, including support groups.²⁶

The Salls Family's Experience

When Cora was born, despite not having a prenatal diagnosis, it was apparent something was wrong. Three days later we got her diagnosis of trisomy 18. The geneticist who gave us her diagnosis was amazing! She simply stated that Cora had trisomy 18. She gave us some information from one of the most reputable organizations, with the most up-to-date research. I asked what this meant for Cora, and she said, "She is going to have a difficult life." This was the truth, nothing more, nothing less. She didn't make assumptions, or tell us that Cora wouldn't live very long. My family is forever grateful for how she set us on the path for what was to be a very difficult, but rewarding, journey.

PATIENT-CENTERED CONCEPT NUMBERS 3 AND 4: PARTICIPATION AND COLLABORATION

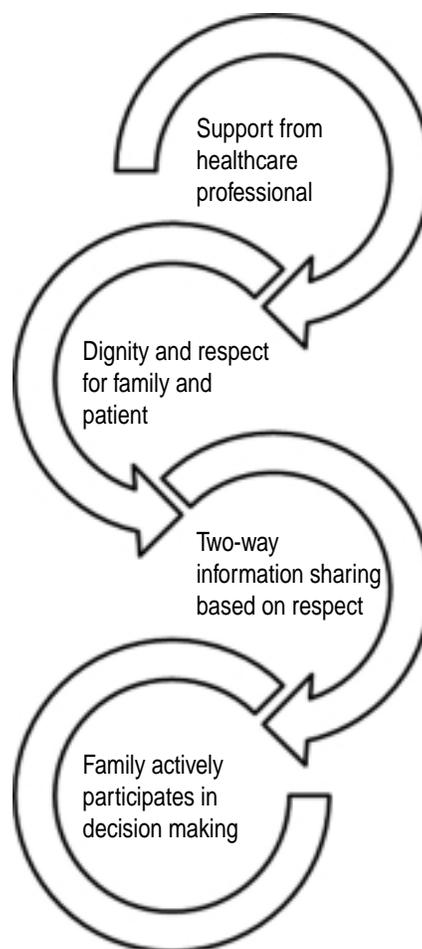
Bias on the part of healthcare professionals can severely limit parents' ability to participate in medical decisions for their child with trisomy 13 or 18, as bias tends to limit collaboration. To increase parents' ability to participate and collaborate, it is essential that healthcare professionals discuss the range of options available in an objective way, even if a particular institution does not provide the type of care the family is seeking.²⁷ An ideal patient-centered care approach avoids coercion, attempts to keep lines of communication open, and establishes relationships with specialists and interdisciplinary teams that can provide coordinated care.²⁸ Even when families and healthcare professionals participate in a shared decision-making model and are able to look beyond their own biases, disagreements can still occur. This is when an ethics consultation may be beneficial. An ethics consultant creates a "moral space" to facilitate discussion between the family and medical team in order to elicit goals and values, ensure that interventions and outcomes are described more effectively, and weigh risks and benefits for a particular child.²⁹ This may be particularly helpful when parents ask for an intervention that the medical team feels is not indicated or is not in the best interest of the child.

The Salls Family's Experience

When Cora was seven months old, she went into heart failure due to her atrial and ventricular septal defects. Prior to this, she had been doing very well, with minimal interventions. She went into cardiop-

ulmonary arrest, and was intubated. We knew the only way to save her life was to have her transferred to a medical center that could do the necessary cardiac repair. Her heart repair would normally be considered simple, as far as heart surgeries go, but due to her diagnosis of trisomy 18, we were not sure we would find a surgeon who would accept her case. We waited for days until we finally convinced a surgeon to operate on her little heart. That was two and a half years ago, and today Cora is doing great! She is learning to walk and is attending school. I still cannot fathom the thought of denying her a lifesaving surgery based just on the diagnosis of trisomy 18.

FIGURE 1.
Patient-Centered Care for Children with Trisomy 13 or 18



This graphic is based on the authors' interpretation of M.J. Barry and S. Edgman-Levitan, "Shared decision making—pinnacle of patient-centered care," *New England Journal of Medicine* 3, no. 9 (2012): 780-1.

CONCLUSIONS

Not all cases turn out as well as Cora's. However, Cora's case provides a good example of shared decision making using the model of patient-centered care. Shared decision making using the model of patient-centered care can help healthcare professionals overcome biases about diagnoses like trisomy 13 and 18. Healthcare providers should encourage a discussion of values and preferences that enhance dignity and respect for the child and parents, provide information in a personalized and objective way, and invite participation and collaboration from the family and the interdisciplinary healthcare teams (see figure 1). Families who feel supported in this way may be more likely to make difficult decisions about treatment plans in a way that is consistent with their core values.

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Caregivers' Bias and Communication at Patient "Hand-Off": The Benefits of the Bring it Bedside Program

Linda Lefrak and Rachael Lamsal

ABSTRACT

This article describes the creation of the "Bring it Bedside" program at Children's of Minnesota. The program standardizes the hand-off of patients' information within patients' rooms, that is, at the bedside, allowing the greater involvement of patients and family members in sharing information about the plan of care. Family members report the program supports their involvement in their child's care and strengthens their trust for their careproviders.

BACKGROUND AND INTRODUCTION

Bias

The word *bias* has been defined as a preconception, partiality, and prejudice about something or someone.¹ A bias may be favorable or unfavorable. It is further described as a tendency to believe that some ideas and people are better than other ideas or people.² The belief that one's own ideas are better than another's may result in treating others in a negatively biased way.

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In healthcare there is concern about what is called *caregivers' bias*, that has the potential to adversely affect the patient-caregiver relationship (trust) and the delivery of care itself. Bias can be both explicit and implicit. *Explicit bias* is when an individual is consciously aware that she or he holds a belief about a person. *Implicit bias* is a belief about a person that is unconscious. Both types of bias may play a role in how a caregiver treats a patient, impact the building of trust, and lead to problems in the delivery of care.³ Bias can occur in the healthcare setting due to gender, race, religion, social status, education, and age.

Bias can also occur when there is a gap in collaboration.⁴ In pediatric healthcare, such a gap can occur when a family makes a decision about a treatment for their child that a nurse does not understand or think is appropriate. A nurse can project a conclusion that has a root in bias about the family and their treatment decision. Such conclusions can lead to conflict if information about the patient that is shared is incomplete or is communicated with bias by another nurse.⁵

The ethical framework for nursing practice includes respect for persons that is nonjudgmental and fair.⁶ Nurses must strive to promote the autonomy of patients—the right of patients to their own views, and to take actions on their views. In pediatrics, this

may become difficult because parents are presumed to be the best decision makers for their child.⁷ Lastly, nurses are expected to keep promises, practice fidelity, tell the truth, practice veracity, and treat people evenhandedly—with justice. These principles are the ethical framework for nursing and are fundamental elements for the delivery of care. They can affect caregivers' bias. Patients and families develop trust for their nurse, if he or she demonstrates respect for the patient and family. Providing competent care, allowing patients and families to be involved in care and make decisions, telling the truth, keeping agreements, being consistent, practicing compassionate listening, and maintaining an open dialogue are the foundations on which trust is built.⁸

Patient “Hand-Off”

In an article entitled “Ethics of Shift Report,” Cynda Rushton points out that patient “hand-off” has the potential to result in the transmission of incorrect information regarding patients and family members.⁹ *Patient hand-off* is the process of passing the responsibility for care of a patient from one healthcare professional to another. In this article, it refers to two nurses who transfer care for a patient between shifts. In her article, Rushton describes the ethical framework of the patient hand-off (the shift report). Rushton points out that the hand-off process can result in a “vehicle for gossip, disrespectful communication and blame, each with the potential for undermining relationships and trust.”

The potential for nurses to discuss and repeat unverified facts, assumptions, and opinions can become a source of bias in delivering care to patients and their family members. Such biasing communications may be an expression of nurses' moral distress and burnout, which have been linked to the care of patients who are critically ill, have decreased decision-making capacity, and who are receiving care that, in the nurses' perception, is nonbeneficial, or when the burden of care seems to outweigh its benefit.¹⁰ Similarly, the use of labels to describe patients at the hand-off (for example: “a real pain,” “belligerent,” “a sweetheart,” *et cetera*) may bias a receiving nurse's perceptions of a patient and family members.

Bias, then, should be understood and discussed by nurses to create an ethical framework for the delivery of care, and to guide communications during patient hand-off. This article will discuss the ethical issues of the patient hand-off. The article will also describe how two interventions—standardization of the hand-off process and completing the hand-off at the bedside—were implemented through

the “Bring it Bedside” project at Children's Minnesota (Children's) to reduce bias and ultimately lead to improved quality of care.

CHILDREN'S “BRING IT BEDSIDE” PROJECT

Background

In 2016, the nursing strategic plan at Children's included an initiative to improve the process of patient hand-off, using a standardized format and bringing hand-off to the patient's bedside. This practice change project was implemented through a shared governance model that includes the input of more than 200 clinical nurses. The project was titled “Bring it Bedside.” The time and resources required were supported by nursing leadership and advanced practice nurses.

Bring it Bedside began with a survey of clinical nurses to assess attitudes and concerns about the hand-off process then in use. It was also used to determine if nurses felt a change was needed. The survey went out to all inpatient nurses on all campuses including St. Paul, Minneapolis, Minnetonka, and the Special Care Nursery at Mercy. The survey consisted of 11 questions, and respondents had an option to provide additional comments. The survey results confirmed that a new process for patient hand-off was essential. During the preliminary implementation process, concerns were identified by clinical nurses that the process then in use for patient hand-off carried a risk for creating bias.

This led to more work to identify the ethical issues involved in patient hand-off. An article by Rushton in 2010 listed the following six strategies for ethically grounded patient hand-off:¹¹

1. Monitor language and tone: be mindful about the words used to exchange information, and work with your colleagues to identify wording that is unclear, hurtful, judgmental, or critical.
2. Challenge assumptions: question information that is not objectively supported.
3. Be alert to the presence of gossip: this may be an indication that there is a need to address an aspect of care or the external environment. Consider consultation with another nurse, manager, or educator if this is of concern for a particular patient.
4. Develop professional norms: hold each other accountable to the process and respect of the process, make it a part of the unit culture to support the respect of persons during hand-off.
5. Use a standard framework to address essential patient information and reduce the sharing of non-essential or inappropriate information to

improve efficiency and maintain respect for persons.

6. Decide on a “need to know” policy: determine what information needs to be shared and with whom.¹²

Through the use of Rushton’s article, the Bring it Bedside project assisted in decreasing bias and ethically grounding hand-off through two major components: (1) standardization of the hand-off process and (2) completing hand-off in the patients’ room—at the bedside. Standardization of the hand-

improvements in the continuity of patient care and the ability to provide accurate information to an oncoming caregiver.¹⁵ Common sources of bias for nurses include an error in understanding or not following a standard procedure.¹⁶ Standardizing the format for hand-off led to unit-based discussions on the essential content social information on the family and patient. The standardized nursing hand-off form design required that nurses gain consensus on “need to know” social information that was essential for the nurse who was assuming patient care responsibilities.

Standardizing the format for hand-off led to unit-based discussions on the essential content of social information on the family and patient.

off process was supported by Rushton’s strategies 4 through 6, while hand-off within patients’ rooms supports strategies 1 through 3.

METHODS

Once the survey data were shared and a review of the literature was completed, work began with individual units to develop a new process for patient hand-off. Nurse representatives from every unit are part of the shared governance structure that is in place at Children’s. These clinical nurses are joined by nursing managers, supervisors, clinical educators, and advanced practice nurses (clinical nurse specialists and clinical practice specialists) to form unit councils. These unit councils developed standardized forms and education plans for their individual specialty areas.

Standardization

The standardization of patient hand-off is broadly supported by several agencies and safety initiatives including the Institute of Medicine, the Joint Commission, the World Health Organization, the Accreditation Council for Graduate Medical Education, and, most recently, the American Academy of Pediatrics.¹³ Research indicates that standardization is a proven way to reduce adverse events related to breakdowns in communication between healthcare providers.¹⁴ With implementation of such standardization, authors have reported dramatic

The standard format selected and implemented at Children’s was the Situation, Background, Assessment, Recommendation (SBAR) form. This tool provides a template to guide the hand-off of essential, objective patient information that is specialty specific. This standardized form sets the expectation of what one nurse needs from the previous nurse. Each unit council developed SBAR content using essential data that were identified by clinical nurses in consultation with nurse educators, the nursing literature, and clinical experts (advanced practice nurses). The use of a standard framework works to reduce the sharing of extraneous, inappropriate, or inaccurate information that can lead to bias.¹⁷

Once the content of the form was determined, unit councils and clinical nurses met to operationalize the information to reduce confusion and gain consensus on what each element of the form meant. For example, in the Assessment section, nurses agreed that information communicated from a systems approach would be for exceptions or abnormal findings only, and not include a listing of findings within normal limits. Another example included discussion about what social information was essential and should be included in hand-off. Although this discussion continues, it has been concluded that hand-off should include the names of the primary caregivers, their visiting patterns, their expressed unique requests/goals, and any additional pertinent information such as the need for interpreters or identified learning needs. The elements of

social hand-off have the greatest potential to contribute to bias. Therefore, there is ongoing evaluation and discussion on how to balance the benefits and burdens of sharing social information during hand-off, with the ultimate goal of sharing only information that is relevant to the care of the patient.¹⁸

Bring it Bedside

The second component of the Bring it Bedside practice change was handing-off patient information within a patient's room—or at the bedside. This change supported Children's care delivery system of patient- and family-centered care through patients' and families' involvement in the sharing of information about the plan of care.¹⁹ The literature reports that patients and families involved in a nursing hand-off have a better understanding of the plan of care and improved satisfaction with communication during their hospital stay.²⁰ Families also reported that a bedside hand-off process supported their involvement in their child's care and strengthened their partnership (trust) with their careproviders.²¹ Since bias often can occur when a patient and family are categorized, a face-to-face bedside discussion improves the accuracy of the information received and allows questions from families, should the information not be accurate. This strategy of bringing hand-offs to the bedside has been reported to reduce implicit bias through a nurse's ability to ask questions and better understand the patient and family's point of view and improve everyone's understanding of the plan of care.²² Involving the patient and family in the hand-off is a means of diminishing bias and building trust between the health-care team, family, and patient.²³

As bedside reporting requires nurses to concentrate on their communication so that they accurately relay only pertinent objective patient information,²⁴ deliberate practice and simulation are being added to education for both newly hired and currently employed nurses. Both simulation and deliberate practice allow nurses to identify how to best communicate at the bedside, with each other as well as with patients and families.

IMPLEMENTATION OF RESULTS

After the first quarter of organizational implementation, the Bring it Bedside project has not only seen an improvement in the quality of patient care, but also in patient and family satisfaction. Data are currently being gathered through patient and family focus groups, as well as patient satisfaction sur-

veys related to nursing communication, and incident reports in which patient hand-off was a contributing factor. Bedside reporting will be evaluated over time by nurses, patients, and families to continue to support and improve this practice change.

CASE STUDIES

The following two case studies are patient hand-offs that did not follow the Bring it Bedside model. Either the component of standardization or patient and family involvement at the bedside were missing and led to caregiver bias.

Case Study 1

A 21-day-old boy was admitted with severe hyponatremia, dehydration, and weight loss by air transport. The parents were en route from more than 100 miles away, and little medical history arrived with the transport team upon the patient's arrival. Social information confirmed included the patient's name, date of birth, parents' names and address, along with laboratory information from the emergency department where the baby had initially been presented for evaluation. Test results in the intensive care unit documented sodium of 172, abnormal renal function, and brain imaging revealed some hemorrhaging in the ventricles. The plan of care included several consults with the Social Service Department and a rehydration plan allowing for a slow lowering of the sodium, and brain monitoring with a 24-hour electroencephalogram (EEG).

Several hand-offs occurred between nurses before the parents arrived. These hand-offs included a review of the medical plan, labs, medications, EEG information, as well as fluid and verification of the intravenous (IV) site. The hand-off also included information about the parents, their ages, where they lived, that this was a first baby, and that they were en route. The hand-off included additional discussion that speculated about why the parents had not sought medical help sooner. Nurses expressed concerns about the parents' judgment because they had allowed the child to become so ill. During team rounds, there were extensive discussions about the need to contact Child Protective Services and presumed neglect by the parents.

On arrival, the parents were evaluated by the Social Service Department and interviewed by the medical team. The parents gave detailed information about their baby's birth and visits to the pediatrician, as well as three visits to urgent care and eventually to the emergency department in their small rural hometown. Medical records were eventually

obtained to support this history and included instructions to change formula and take their son home. The parents were young and had limited financial and social support. The information shared during hand-off prior to their arrival had been inaccurate and unverified. Hand-offs had included irrelevant information sharing and bias about these parents. This bias took many days to “undo” and longer to rebuild trust between the parents and caregivers.

Analysis. While the standardized Bring it Bedside project would not necessarily have prevented this family from being viewed with bias, the discussion about the need for verified information to be used within hand-off will continue to support the process of using information that is standardized, to reduce assumptions. Any discussion of socially pertinent information must be verified, and, when done at the bedside, allows for family interaction and the confirmation of information. There is the potential to improve the trust relationship among nurses, families, and patients when the hand-off process is focused on objective, essential information. Hand-off at the bedside enables families to better trust nurses when they hear the review of their child’s care and plan for the day.

Case Study 2

E.M. was a 10-year-old girl with a complex medical history recently complicated by an inability to take in adequate fluids and nutrients orally. She was admitted through the Children’s Emergency Department, with a chief complaint of failure to use a newly placed gastrostomy tube (GT). Her mother was an adult obstetric nurse and her father was a family practice physician. After an initial history was taken from the parents, a new nurse came to assume care and the hand-off was completed outside the room. The hand-off included the nurse’s physical findings and an ordered imaging study to determine tube placement. Once the imaging was done, it was determined that the tube required replacement, and the surgeon was notified. The plan was to discharge the patient once she had recovered from the new tube placement. The new, skin-level tube was placed successfully, and the child was transferred to the post-anesthesia care unit (PACU) for recovery and prepared for discharge home. A book for parents on the care of the new GT was given to the parents, and they were asked to sign a form indicating that they had understood the home-care instructions. The father was beginning to sign the paperwork when the mother interrupted, teary and visibly apprehensive, and said, “We do not know how to use this tube and

weren’t even sure how to use the last one.” “This tube misplacement might not have happened if we had more teaching and time to learn the care before our last discharge.” The PACU nurse then arranged to delay the discharge and contacted a coworker who could assume the care of the patient and complete the teaching. The surgeon was contacted about the potential need to have the child stay overnight to complete the instruction for the parents.

Analysis. In this case, the bias was that medical professionals need less instruction about tubes than other parents. The hand-off without the parents present did not allow for questions to be asked. What parents want and need cannot be assumed based on profession, age, education, or social status. Including families in the hand-off process presents an opportunity for the parents to hear the plan of care and ask questions. If the parents in this case study had heard the plan to discharge immediately after recovery in the PACU, their concerns and needs could have been addressed earlier.

SUMMARY

Children’s utilized Rushton’s article, including the six strategies to decrease bias through the Bring it Bedside project. The two major components were standardization and the completion of patient hand-offs within the patient’s room. Standardizing nursing hand-offs promotes structured discussion of only essential and confirmed information about patients and families. It improves the quality, safety, and continuity of patient care. Bringing patient hand-off to the bedside decreases the risk of caregivers’ bias by discouraging unsupported assumptions and false conclusions from being communicated to the oncoming nurse and by allowing the family to correct any false information. The Bring it Bedside project enhances the principles of truth-telling, justice, promise keeping, and respect for persons. The ongoing presence of patients and families during the hand-off helps to prevent the creation of negative bias.

PRIVACY

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

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*The Family Voice***Mother Love***Perla Morley***ABSTRACT**

The author blogs on her experience as a mother of a child with severe health disabilities.

“This is what Caleb needs,” my son Daniel said as he pointed to a quote from the little notebook he bought at a thrift store that day a few years ago: “Mother love is the fuel that enables a normal human being to do the impossible.”

“And what is the impossible for Caleb?” I asked. “Walk, talk, see.”

Just as my son, at first sight I took this to mean that my love could help his disabled brother do the impossible, as if by magic, it could suddenly transform me into a modern-day Jesus who could make his brother walk, talk, and see.

That is not, obviously, what Marion C. Garretty meant when she wrote these words, but Daniel got something right—Mother love is powerful.

Mother love empowers mothers. It enables us to do what is seemingly impossible, which in a mother’s day-to-day could simply mean getting up for the third time in the middle of the night. Mother love helps mothers with the simple things of life, but it also sustains us and makes us push forward full-force for the sake of our children when adversity strikes.

“I don’t know how you do it,” people often tell me about my chronic lack of sleep—Mother love.

“I don’t think I could bear what you are going through,” one of my coworkers confessed when

it seemed like Caleb could die any minute—Mother love.

Mother love carries a child that will most likely die.

Mother love sees beauty in the presence of multiple abnormalities.

Mother love endures seeing her child go through chemotherapy.

Mother love learns to change a trach.

Mother love bags her child to help him breathe. Mother love operates more than one piece of medical equipment.

Mother love carries her child even if he weighs 70 pounds.

Mother love gives CPR.

Mother love speaks medical lingo.

Mother love celebrates milestones.

Mother love is OK with no milestones.

Mother love loves her healthy, bright child.

Mother love loves the profoundly delayed.

Mother love accepts.

Mother love rebels.

Mother love makes difficult decisions.

Mother love chooses aggressive interventions.

Mother love chooses comfort care.

Mother love fights to keep her child alive.

Mother love lets him go when it is time.

The list goes on and on about all Mother love can do. You were right, my son: Mother love is the fuel that enables a normal human being to do the impossible. I am that normal human being. My love cannot make your brother walk, talk or see, but it will help me be there for him. And, in the end, Mother love will help transform his life into the best that it can be.

Perla Morley is the mother of a child who is treated at Children’s Minnesota, who blogs at <http://perlapaulmorley.blogspot.com>. This blog is reprinted here with her kind permission.

Desperation. Exhaustion. Fear.

Julie Martindale

ABSTRACT

The mother of a medically complex child explains how she lost trust in the child's medical team when the lead physician did not present all of the options for the child's care. Over a period of years, the medical team regained the parents' trust with their compassion, honesty, and lack of bias.

These are a few of the emotions that thickened the air when my child was in the depths of struggling for his life in the hospital. These emotions were not new to us as parents of a medically complex child. We had been there often. Our son became a part of our family right after his first birthday. We knew when we committed ourselves to him that his life was not going to be an easy one. He was born healthy, or so it appeared, until a fever ravaged his brain and changed the course of his life.

One of our first tasks as his parents was to assemble the dream team of doctors and caregivers in whom we could put our confidence, in that they might be able to alleviate the struggles that our beautiful son was facing. He had feeding issues. He had breathing issues. But underlying it all, it was the neurologic damage that didn't allow his brain to control the life-sustaining functions of his seemingly perfect body. The profound damage to his brain caused severe neuro-irritability, and it was intensely painful to watch.

When he first came home to us, we held tight to a little boy who did just one of two things: sleep and scream. There was no inbetween. His neuro-irrita-

bility created a helplessness in us that we had never experienced before. We went to the hospital in hope of getting some answers.

When we walked through the emergency room doors, we were already weary and overwhelmed. We were swimming in the deep, dark depths in an ocean of parental despair. We had one job, and it was to protect our son from pain. It was to keep him alive, and we were failing. Some of the dream team that we had enlisted to care for him were willing to wade in the water with us. Some dove in and swam alongside us. A few threw us a life preserver to help us get some rest. Others walked quickly past along the shore and did not dare enter the waters with us, walking away from the child who was not going to have a good outcome, who would never walk or talk or even breathe well on his own. No use in swimming in water when the odds of coming out alive were slim.

Admission to the hospital led to two weeks in the intensive care unit. Difficulty with feeding became the overpowering issue. It was a diagnosis of exclusion, each specialist declaring that it was someone else's issue. With each day at the hospital, we came more exhausted, frustrated, and desperate for answers. I just wanted our son to stop screaming, to stop hurting. We knew he would never be healthy in the way that the world would define it, but I needed to believe that we had a team who was committed to ease his pain and give him the best outcome possible.

And then one day, a new team walked in. I was alone at the hospital, and my child had finally fallen asleep after hours of screaming. Although I had met most of the team of professionals, I couldn't tell you who was there that day. The lead doctor was some-

Julie Martindale is the parent of a medically complex child treated at Childrens' Minnesota.

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one I had only heard good things about. I was tired, desperate, and overwhelmed. Was my son dying? Was he going to continue to be miserable until the day he died? All of that scared and saddened me, and I felt I owed him more.

The new doctor quickly began introducing himself and the rest of the team and reminded me that I had met many of them before. There were four of them, and only one of me, and what was left of me

give me honest, accurate, and unbiased information so that we could make an informed choice that day. That opportunity was lost.

Not only did I feel overpowered by this doctor and his team, I felt the loss of not having someone by my side to help me accurately hear what was being said. I wished that the news could have been delivered at a mutually convenient (or ultimately inconvenient) time for all involved. Making this

I did not feel I was given the options in an honest and unbiased way. . . . I lost that trust instantly when I was not given all the options of care for my son that day.

was fragmented and distraught. As they were sitting by the bedside, the lead doctor began by telling me that my son's body was most likely shutting down. It is the words ". . . and you don't want him hooked to machines, do you?" that have stuck with me since that day. That was the moment I began to doubt the team who sat before me.

Skepticism. Mistrust. Fear.

"Hooked to machines"? In an attempt to help me understand the seriousness of my child's condition, these words were used, not out of lack of caring or maliciousness in any way, but I didn't trust anymore. It was not the devastation of the news that I was receiving that day, it was that I did not feel I was given the options in an honest and unbiased way. This doctor didn't know my son and he didn't know our family. He didn't know that we had a young daughter at home who required a ventilator. He didn't know we understood what it meant "to be hooked to machines" in a way that wasn't shown in the latest television drama. We lived it with a child who had a beautiful quality of life. It did not mean that the choices that we made for our daughter would be the same we would eventually make for our son, but it was important to us that we feel a sense of trust in the team who was asking us to allow a do-not-resuscitate/do-not-intubate (DNR/DNI) order to be signed for our son. I lost that trust instantly when I was not given all the options of care for my son that day. The words "hooked to machines" told me more than the doctor could have ever imagined. I heard a biased explanation intended to persuade us to make a decision that he felt was best for our child. But I needed to be given all the options that were open us as we moved forward. I needed someone to

decision was not an emergency. I wished that I had had time to make sure my husband was there to hear this, so that I didn't need to be the one to summarize the news for him. In such an emotionally challenging time, I no longer trusted myself to accurately convey information. My son's father deserved to hear this news from the doctors, not through me.

Shortly after that encounter, another doctor was able to find a combination of medications that eased my son's pain. When we left the hospital, we did not leave with a DNR/DNI order in our hand. We did eventually regain the trust of these doctors who earned our trust with their honesty, knowledge, and respect for us. Over the years, those doctors got to know our son well. They took the time to get to know our family, too, and they understood our values, weaknesses, and our strengths. They were not afraid to share all of the options that were before us when deciding what was best for our son. They helped us to listen to our son's voice despite the fact that he never spoke a word. In the end, we felt our son's life was honored and respected by his healthcare team.

Undying love. Overwhelming grief. Unexplainable peace.

Six years later, with guidance from our team, we made the decision that we didn't want to be in a hospital when our son took his last breath. We knew that extreme life-sustaining measures were not in his best interest. When our son took his last breath, in our arms, in our home, with his family surrounding him, it was exactly as it was meant to be. He died in a way that honored his life and beautiful spirit.

Delivering difficult news is never easy, and it doesn't always go as planned. But, if done in a spirit

of compassion, honesty, and lack of bias, a family's right to choose what is best for their child can be honored. We fought for our son's dignity in life, and now live at peace knowing we made the best informed choice for his death. We are free to grieve his unthinkable loss without the doubt that we had not been presented all care options. Our family can grieve in peace.

Perfect “Children’s Parents”

Stacy Holzbauer

ABSTRACT

The author, the mother of hospitalized twin daughters, probably felt more comfortable in the hospital than most parents, due to her medical background. Members of the medical team told her they felt they could communicate more easily with her because she “got it.” While the author is grateful for the care and support that her family received, she thinks about other parents in the hospital who may have lacked her medical background, or whose child was not doing as well, or who couldn’t be at the child’s bedside every day. The author urges medical staff to consider, to a greater extent, their possible biases against parents who are not “perfect parents” or who don’t seem as able to “get it.”

My husband and I were the perfect pediatric hospital parents. White, middle-class, first-time parents with good insurance who would do anything necessary for our twin daughters. Dutifully taking notes, asking questions, and at the bedside every day for hours. Add to that, I had a medical background and could speak the language. “Do you have a medical background?” was frequently asked within five minutes of meeting a new specialist, careprovider, or nurse, followed by the noticeable look of relief when I answered yes. I was immediately welcomed into the conversations about my daughters’ care and in

many cases the tone of the conversation had turned. Not only was I “Mom,” but I “got it.” The care we received was first-class in every aspect. When things went well, we celebrated. When complications arose, I was able to get answers I could understand. Because of the care my entire family received, we will forever be indebted to our amazing care team and are constantly in search of ways that we can give back and thank those who are responsible for the healthy, giggly girls we enjoy today.

So why am I writing about bias, you may ask. During our extended stay, and possibly because of the comfort the care team felt with me, I was privy to some concerning conversations. I remember one afternoon later in our stay—one daughter had already been discharged and the remaining daughter no longer required a nurse of her own—we were sharing a nurse with a family down the hall. My daughter was stable and doing well, whereas the other family was having a tougher go. Their child was a toddler, this was not a maiden visit for the family, and the care team knew them well. After spending the vast majority of her time in the other patient’s room, our nurse stopped by to apologize for not being more attentive. I reassured her that we were fine and I knew how to push the call button if we needed anything. She thanked me and then mentioned that the other family just didn’t “get it” the way we did. “You all are such a breath of fresh air compared to some of our other families.” I realized that she was frus-

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trated, but in hindsight I can't help but wonder what were the assumptions and communication barriers that were in play. Was this a family who didn't have the strong support system that we did and didn't have the luxury of being at the bedside every day? Were they trying to juggle a job and other kids and just didn't have the bandwidth to fight with a toddler who wanted to pull out the intravenous line? I believe, at a basic level, all parents want the best for their children, but everyone has stressors that pull them in different directions. Add in a hospital stay and a foreign language of medical terms and you have the makings for conflict. Several studies report that families of patients who are in the intensive care unit suffer from posttraumatic stress disorder.¹ So, if you find yourself repeating the same directions to your patients over and over again, it may be that they truly didn't understand the first three times. Sometimes it is necessary, when people don't "get it," to not assume that they don't care, but rather to ask what assumptions am I making that are preventing my message from getting through, or what information do I need from the family to find the appropriate way to communicate?

One of my daughters needed a feeding tube that would bypass her stomach and provide nutrition directly into her small intestine. Unfortunately, she was too small for the commercial tube, and her gastroenterologist concocted a homemade tube within a tube that was literally taped together with a popsicle stick. One wrong move or loose piece of tape could lead to the internal tube coming out and my daughter going back into the operating room to have it replaced. After the team struggled to secure the tube with tape, and two incidents of the internal tube becoming displaced, I asked if I could give it a try. As a farm kid who had multiple opportunities to fix problems with duct tape, I'm proud to say that my tape job held for a month, allowing my daughter to grow enough so she could use the commercial tube. But would every parent have had the opportunity to try? As caregivers, please to ask yourselves why you trust some parents more than others. Are they truly putting their children in danger, or do you not understand their point of view?

Anyone who chooses to work in pediatric medicine has demonstrated a desire to be compassionate and caring. But it is important to recognize the inherent biases that may lead some families to get the rock star treatment while others are left frustrated with their care. Listen to your patients and your parents, and try to understand what barriers stand in their way, rather than assuming you know their story. Through compassion, communication, and

genuine understanding, hopefully all of your families will "get it."

NOTES

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