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Putting Children at Risk in the Name of Religion

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The risk of a newborn having critical congenital heart disease (CCHD) is about 1 out of 100 babies, making it the most common birth defect. If this condition goes undetected, the consequences for the newborn include neurological impairment and death (GlideWell 2015). Fortunately, newborn screening tests using pulse oximetry are noninvasive and painless—as easy and simple as taking an infant’s temperature with an ear thermometer—and often do not require parental consent. Yet some states by law allow parents to refuse CCHD screening because of religious objections. Hom and colleagues argue the parental right to these exemptions should be honored because forcing compliance is a greater moral harm than the potential benefit to newborns. Hom and colleagues make three important claims with which we agree and which we use to draw a different conclusion.

First, parents who exercise this exemption are wrong from a medical perspective and are exposing their children to unnecessary risks (Hom et al. 2015). It is well established that interventions for a minor that involve risk require the informed consent of the parent or guardian. But in the case of pulse oximetry, which is used in the hospital to check oxygen saturation levels for many major and relatively minor medical problems, there is virtually no risk and if a diagnosis is made medical treatment can greatly benefit the baby. Granted, there are other values that play into a benefic-burden analysis, but the basic facts of the matter show a clear benefit with no burden for the baby. Second, the benefit–burden ratio is so one-sided in favor of the benefit that in states where screening does not require consent, Hom and colleagues agree, it is permissible to do the test without consent (Hom et al. 2016). So the only compelling reason to take seriously a parental right of refusal for religious reasons would be a provision in the state law, which sanctioned the right of the parent to exercise the religious exemption. Third, there is no known major religion that would oppose such tests (Hom et al. 2016). In fact, it is hard to imagine a possible religious basis for a parental refusal of CCHD screening on religious grounds. Its seems more likely that in effect states that provide a “religious exemption” for parents to refuse CCHD screening on religious grounds are really giving parents an “out” for any possible inclination they may have to refuse a simple, safe screening intervention.

Hom and colleagues make a thoughtful and nuanced analysis to make their case. Given the low probabilities of finding an abnormality from CCHD screening, and the fact that there are more than medical interests at stake, there would admittedly be some harm to the parent and indirectly to the baby if the parent had “to deal with a serious disruption of their parenting, plus anger and despair about their values not being respected and their wishes ignored” (Diekema 2004). But we disagree that a benefit–burden analysis supports allowing parental refusal based on a religious exemption.

There is an ethical obligation to provide the standard of care to newborns to reduce future risks of morbidity and mortality. CCHD screening clearly meets the criterion for mandatory or standard of care screening set by the President’s Council on Bioethics in that the disorder “must pose a serious threat to the health of the child, its natural history must be well understood, and timely and effective treatment must be available, so that the intervention as a whole is likely to provide a substantial benefit to the affected child” (http://grn.nlm.nih.gov/condition/critical-congenital-heart-disease). The effects of untreated CCHD are very serious for the baby, which account for about 30% of infant deaths due to birth defects. Though the baby may appear normal at the beginning of life, problems will soon arise that could include delayed development, and eventually heart failure and premature death (http://grn.nlm.nih.gov/condition/critical-congenital-heart-disease). Not only will the baby’s life be affected in terms of impaired health and quality of life, the parents and family will be seriously affected by having to assume the role of caregivers. Moreover, there will be the additional and unnecessary burden to the health care system, as the baby will likely require frequent medical care. It is hard to fathom why such burdens, even if only remotely possible, should not be precluded if there was an extremely simple, noninvasive way to do so. In fact, should the infant return to the hospital with signs of respiratory or cardiac insufficiency, more than likely the very first thing that the medical team will do is place a pulse oximeter to check oxygenation. Could there possibly be a religious objection then? It is hard to imagine.

Given the simplicity and ease of CCHD screening there is no rational reason why states should require consent or
provide religious exemptions to allow parents to refuse. Because of the preponderance of benefits, CCHD screening does not rise to the level of requiring consent by the parents. There are no risks for the baby in the screening process, and all of the possible effects, if there is a positive result, would be favorable in that medical treatment would be initiated sooner rather than later. Harsh and unnecessary sequelae would be avoided. Instead of focusing on states that provide a religious exemption and offering cover for bad public policy, we believe our strongest recommendation should be that all states remove requirements for parental consent and eliminate the religious exemptions, and just do them as a matter of course.

In an era of misinformation about the health care system, religious exemptions that have no correlation to any religious traditions are problematic as a basis for parental rights. Our worry is that religion is being used as a cover to justify any kind of personal act of defiance or noncompliance that may be directed against any type of authority. To the extent that states were to allow parents an exemption from their baby’s CCHD screening, it would make more sense just to call it a “personal exemption.” Hom and colleagues admit the growing difficulties for society and the healthcare system when religious exemptions that have no traditional or communal basis for belief become so idiosyncratic. Whatever the reason behind a parent’s possible refusal, we have serious questions about it being religious in nature. In fact, given the baseless reasons why any parent could refuse CCHD screening, the use of religious exemption could be viewed as an abuse of individual rights and demeaning to the importance of religion.

No one can doubt that the medical benefit of CCHD screening to newborns can be achieved by a painless, simple intervention with no harm caused to the baby. Even Hom and colleagues agree that consent from parents is not a moral requirement. Therefore, instead of creating at best a contentious argument to justify idiosyncratic decisions that pose risks to babies in states that grant parents religious exemptions, we believe it is more ethically sound to focus the bioethics recommendation on better public policy. All states should have laws that do not require parental consent for CCHD screening and have no religious exemptions. We should not put children at easily preventable, serious risk in the name of religion, and our bioethical analysis should reflect this broader view.

REFERENCES

Parental Refusal of Newborn Screening for Congenital Hearing Loss

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Newborn screening began in the 1960s as a way to detect metabolic disorders using dried-blood spots. Today, nearly all newborn babies have a blood spot taken and sent to a centralized laboratory for evaluation. Approximately 10 years ago, newborn screening was expanded to include screening for congenital hearing loss (Centers for Disease Control and Prevention [CDC] 2015). Unlike earlier blood-spot testing, congenital hearing loss screening was the first example of a noninvasive, point-of-care newborn screening test. All states now include screening for congenital hearing loss as part of newborn screening (American Academy of Pediatrics [AAP] 2015). Recently, point-of-care testing for critical congenital heart disease (CCHD) using a noninvasive pulse oximeter (a sticker that can be applied while a neonate rests in a parent’s arms) has also been recommended by the American Academy of Pediatrics (AAP 2012) and is now required in the majority of states. Hom and colleagues (2016) examine whether parental refusal of CCHD screening should be allowed on the basis of religious or personally held beliefs.

An interesting, informative, and unconsidered (by Hom and colleagues) perspective on the ethics of parental refusal of screening for CCHD is an examination of the ethical challenges surrounding parental refusal of the initial