

A DIFFERENT VIEW

## Paediatrics-based fetal care: unanswered ethical questions

Stephen D Brown (Stephen.brown@childrens.harvard.edu)<sup>1</sup>, Anne D Lyerly<sup>2</sup>, Margaret O Little<sup>3</sup>, John D Lantos<sup>4,5</sup>

1.Department of Radiology, Children's Hospital Boston and Harvard Medical School, Boston, MA, USA

2.Department of Obstetrics and Gynecology and Trent Center for Bioethics, Humanities, and History of Medicine, Duke University, Durham, NC, USA

3.Kennedy Institute of Ethics and Department of Philosophy, Georgetown University, Washington, DC, USA

4.Center for Practical Bioethics, Kansas City, MO, USA

5.MacLean Center for Clinical Medical Ethics, The University of Chicago, IL, USA

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### Correspondence

Stephen D. Brown, Department of Radiology, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115. Fax: 617-730-0573 | Email: Stephen.brown@childrens.harvard.edu

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Something new is happening in perinatal health care. Many leading children's hospitals are creating fetal care centers as part of the continuum of care that they offer. We, and others, call this the paediatrics-based model of fetal-care. This is in contrast to the obstetrics-based model that offers traditional care to pregnant women and fetuses and has traditionally been the domain of obstetrics services.

The paediatrics-based centers promise parents – and society – better outcomes, but evidence that the centers can fulfill these promises is still pending. Nonetheless, paediatrics-based fetal medicine is not being offered as an experimental protocol, but as a compelling new venture.

Care in these centers will certainly be costly. Whether it will be efficacious remains to be seen. A number of features of paediatrics-based centers magnify ethical complexities. The location of fetal care centers in children's hospitals, rather than in general or women's hospitals, may carry different professional and ethical priorities into the domain of prenatal care. Traditionally, obstetrics has focused primarily on the health and well being of women, while paediatrics has focused on the well being of the child.

Concerns for the well-being of pregnant women and fetuses overlap considerably. When the decision to continue the pregnancy has been made, the interests of mother and fetus are most often aligned. Divergences do occur, however, as in the case of severe preeclampsia, when perinatologists must weigh the risks to the fetus of early delivery with the risks of prolonged gestation for the pregnant woman, or again, when a potentially lethal or disabling condition is discovered in the fetus.

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This raises important questions of whether the professional ethos defining paediatrics will diverge from what has traditionally defined the care of pregnant women. Take, for instance, the case of pregnancies in which a fetal abnormality is discovered. Obstetricians may counsel pregnant women about the possibility of abortion for conditions, such as Trisomy 21, whose severity is nonetheless insufficient to permit paediatricians to discuss withholding of life-sustaining postnatal treatment. As a result, paediatric specialists may perceive their respective obligations to the fetus and pregnant woman differently from obstetrical specialists, or hold contrasting views of maternal and fetal interests and status (1–4). Or again, the possibility of therapeutic intervention before birth may reshape conversations about prenatally diagnosed conditions. How should providers discuss prognosis for a fetus with myelomeningocele or hypoplastic left heart syndrome? The rationale for or acceptability of abortion may not be readily apparent to fetal specialists whose approach to the fetus is presumptively therapeutic.

More broadly, champions of paediatrics-based fetal medicine have strongly emphasized the fetus as a distinct patient who resides in utero (5–7). A traditional paediatric approach may elevate concern for the fetus or future child in ways that has the potential to overshadow concerns for maternal welfare. In fetal medicine centers, physicians who focus primarily on the clinical condition of the fetus might feel that they are less than full fiduciaries of the woman, potentially to the detriment of the woman and her fetus alike. Trends in the reporting of antenatal surgical interventions for fetal conditions underscore this concern: Very few studies have measured short- and long-term outcomes of women who choose to participate in these innovative and highly invasive intrauterine procedures (8).

Focusing on the interests of a fetus introduces other complexities. Concern has been raised that aggressive fetal treatment (e.g. major surgery) might undermine the preferences of the pregnant women. Alternatively, the pregnant woman might request fetal therapy that physicians think is too high-risk for her and too low-yield for her fetus to be medically indicated. Indeed, if experience with end-of-life decision-making is any indication, demand for treatment may be a more common problem than refusal. A woman whose fetus is diagnosed with an anomaly may adamantly appeal for fetal surgery, even when outcome data are lacking, and/or she possesses medical contraindications.

Of course, the vast majority of interventions performed by paediatrics-based fetal medicine specialists are not physically invasive, and many, at least in the near future, will be diagnostic. In these cases, counseling will take the form of complex discussions about the probabilities of various outcomes. Such discussions are rarely value neutral. Counseling by paediatrics specialists may emphasize efforts to inform pregnant women about environmental exposures and physical activities, to advise them about medication use, or to counsel them about the time and place of delivery that would optimize neonatal health. In these realms, too, potential ethical conflicts might be generated when paediatricians, long concerned with child protection, move into the world of obstetrical medicine.

As technologies progress, and as medical management of complex pregnancies migrates toward paediatrics-based fetal care centers, fundamental questions have been left unaddressed: will these centers more strongly emphasize fetal over maternal outcomes? Will they place greater emphasis toward bringing to term pregnancies that will result in children with disabilities? Will they bring subtle pressure to bear on pregnant women to attenuate behavior or undergo risky procedures for fetal benefit? Will they be able to define boundaries of ethical care when parents request or demand interventions in hopeless situations?

Unfortunately, little data on counseling patterns are available to inform policy. Prenatal health care providers from different disciplines may have different professional priorities (or loyalties), although individual moral views and priorities will certainly vary (1–4,9–11). A few studies have demonstrated differences in attitudes regarding prenatal and perinatal care between paediatric and obstetric specialists specifically (3,10,11). No studies in the United States have addressed this question empirically. One analysis of past American Academy of Pediatrics (AAP) and American College of Obstetricians and Gynecologists (ACOG) policy statements suggested that the organizations, at that time, possessed differing perceptions of the nature of maternal responsibilities to the fetus. They also differed about when and to what extent maternal autonomy might be over-riden for fetal benefit, raising concern that paediatric specialists, steeped in an ethos of child protection, may be more tempted than obstetricians to seek judicial approval to override maternal treatment refusals (4).

With scant long- and short-term data about the consequences of interventions, and no prevailing consensus on

an optimal ethical framework to guide prenatal counseling, divergent professional orientations may generate ethical concerns for prospective parents and clinicians alike. Tensions between maternal interests, fetal interests and the interests of the child-to-be, as well as the preferences and values of pregnant women, expectant fathers, fetal medicine specialists and high-risk maternal-fetal medicine specialists, might become more prominent in paediatrics-based centers than in those based in obstetrics centers. New paradigms for understanding the maternal-fetal relationship will likely be needed to achieve consensus on best counseling practices, standards for informed consent, full disclosure of available medical options, and provider transparency on issues of abortion, intrauterine therapy, and the aggressiveness of postnatal care.

As prenatal diagnosis and therapy emerge out of the murky waters of experimentation and into the turbulent domain of standard practice, it is no surprise that weighty ethical issues persist. It took 40 years to reach rough consensus on the most profound questions raised by neonatal technologies. Any current consensus within neonatology has required diverse multidisciplinary input, continued revision to keep up with innovation, and considerable thought about how most effectively to implement the technology, assess outcomes, and formulate a morally coherent response.

The social and ethical controversies that arise in fetal medicine are emerging within a highly charged judicial and political environment. The recent United States Supreme Court decision in *Gonzales v. Carhart* suggests how legal oversight of perinatal decisions might encroach upon doctors' authority to make clinical decisions (12). Moral debates about abortion, maternal-fetal decision-making, neonatal bioethics and research ethics might all come together in paediatrics-based fetal care centers, with such centers, in essence, serving as the workshops in which we develop new understandings of these complex situations. Indeed, because such centers are developing without robust evidence for their efficacy, they may have social, ethical and economic impact long before they have broad medical impact. Physicians at such centers should anticipate controversies and develop explicit and transparent policies for dealing with them.

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