

Marilyn E. Coors and Susan F. Townsend, "Supporting Pregnant Women through Difficult Decisions: A Case of Prenatal Diagnosis of Osteogenesis Imperfecta," *The Journal of Clinical Ethics* 17, no. 3 (Fall 2006): 266-74.

# Supporting Pregnant Women through Difficult Decisions: A Case of Prenatal Diagnosis of Osteogenesis Imperfecta

*Marilyn E. Coors and Susan F. Townsend*

**Marilyn E. Coors, PhD**, is an Assistant Professor of Bioethics at the Center for Bioethics and Humanities at the University of Colorado at Denver and Health Sciences Center in Denver, Colorado, [marilyn.coors@uchsc.edu](mailto:marilyn.coors@uchsc.edu).

**Susan F. Townsend, MD**, is the Medical Director of the Neonatal Intensive Care Unit at Memorial Health System in Colorado Springs, Colorado. © 2006, *The Journal of Clinical Ethics*. All rights reserved.

Obstetrical healthcare professionals strive to promote shared decision making with patients during pregnancy and delivery. In most cases professionals provide comprehensive information that promotes collaborative patient decision making and enhances overall well-being. Prenatal testing sometimes reveals information that effects the decision. The testing can lead to situations of substantial uncertainty in which the values of pregnant women are overwhelmed by the influence of healthcare professionals.

## CASE PRESENTATION

A routine ultrasound at 21 weeks of gestation had shown evidence of a fetus with multiple congenital fractures, resulting in a diagnosis of Osteogenesis Imperfecta Type II (OI). OI is a potentially lethal genetic condition associated with defective maturation of collagen. The expression of the disease varies from mild osteoporosis to brittle bones, blue sclera, deafness, and early death.<sup>1</sup> Some forms of OI have recently been treated experimentally with pamidronate to increase bone density, symptomatically resulting in fewer fractures and more comfort.<sup>2</sup> Life expectancy and quality of life vary depending on the severity of the condition. There is no definitive antenatal genetic marker(s) to predict severity of OI, and some infants who are diagnosed prenatally with the most severe forms turn out to be more mildly affected and survive.<sup>3</sup> Type II OI is the most severe form, with perinatal death caused by respiratory failure.

When faced with the early diagnosis of OI in her fetus, the pregnant woman in the case under discussion chose to continue her pregnancy with the understanding that her child might be compromised or live only a short time after birth, depending on the severity of the disorder. The prognosis for this particular fetus was uncertain, even among the physicians and staff who had seen the ultrasound. The decision to continue the pregnancy was not challenged by the healthcare team, even though it may not have been the course of action that they would have recommended.

At 34 weeks, this case was the focus of ethics rounds in a tertiary care hospital because it was time to consider the mode of delivery. The obstetrician strongly recommended a vaginal delivery because she felt that the infant would not survive more than a few hours or days, as ultrasound findings in this fetus suggested the most severe form of OI. Data from a regional study of the medical records of 55 deliveries of infants with the most severe form of OI revealed 24 of 31 babies delivered by cesarean section and 21 of 24 delivered vaginally died within two weeks of birth.<sup>4</sup> Given these observations, the obstetrician did not want to jeopardize the future reproductive health of the pregnant woman with what the doctor considered "an unnecessary, potentially risky and expensive surgery" for the mother. As an alternative, one of the staff suggested that a cesarean section might be an option that would increase the chance of a live birth without additional fractures. It is not unusual to recommend a cesarean delivery for a fetus with evidence of fractures or deformities,<sup>5</sup> although this is debated.<sup>6</sup> As the case discussion continued, it became clear that the primary obstetrician was not open to further consideration of a cesarean for the reasons stated above.

A clinical geneticist who was present emphasized the difficulty of determining the actual severity of OI or the length of time the infant would survive based on an ultrasound diagnosis.<sup>7</sup> She stated that even with biochemical testing and x-rays after birth, it is difficult to predict the phenotype of an individual infant; the infant's clinical course and evidence of respiratory failure are more relevant than laboratory or imaging studies. The geneticist was currently treating several patients with severe forms of OI who were 19 and 20 years of age.

## PRENATAL DIAGNOSIS WITH ULTRASOUND

Ultrasound screening is routinely performed during the first and second trimesters to provide information that professionals and families use to guide care throughout pregnancy. It often permits pregnant women to know whether an anomaly is present in their fetus and increases the information available to guide various courses of action.<sup>8</sup> Ultrasound may be the initial indicator of anomalies in a pre-viable fetus, and it is often followed by more extensive testing to clarify diagnosis and/or prognosis, including karyotyping and searches for additional anomalies. Occasionally, fetal ultrasound surveillance can be misleading, or misinterpreted, causing stress and anxiety for women whose fetuses turn out to be normal or mildly affected.<sup>9</sup>

As clinical information is gathered, the weighty decisions of whether or not to terminate a pregnancy, attempt intrauterine therapy, or support a pregnancy to term must be addressed. Some women, when confronted with the diagnosis of a pregnancy complicated by severe fetal anomalies detected by ultrasound, opt for termination of pregnancy.<sup>10</sup> Professionals typically honor this decision for a pre-viable fetus with severe anomalies.<sup>11</sup> In third trimester pregnancies, others choose non-aggressive obstetric management when there is little benefit for the fetus.<sup>12</sup> A number of women use the information to prepare for a difficult pregnancy outcome and choose treatment or delivery options with the potential to benefit their fetus. When a pregnant woman's choice gravitates towards fetal over maternal benefit, professionals sometimes find it more difficult to support decisions to continue a pregnancy with severe and potentially life-limiting fetal anomalies.<sup>13</sup> This may be explained by evidence that some families do not perceive severely compromised health status to be as concerning as healthcare professionals and typically prefer more aggressive support than their providers would.<sup>14</sup> Many families embrace the challenges of caring for an impaired infant. For other families, the birth of an impaired infant is too economically or emotionally onerous or may dash their hopes and dreams for a "perfect" child who would meet certain predetermined criteria.<sup>15</sup> Professionals should respect both perspectives as long as the treatment decisions are medically and ethically appropriate.<sup>16</sup>

In addition to the above options (termination or continuation of a pregnancy), a pregnant woman can decide not to screen her fetus for many reasons including the perception of over-medicalization of her pregnancy. This third option avoids anxiety-generating elements that a potential diagnosis of fetal anomaly can entail, but, likewise, a decision not to screen deprives her of potentially valuable information. False-positive and false-negative obstetrical ultrasound exams, the uncertainty of prenatal testing and diagnosis, and the risk of depression following the termination of a pregnancy are all possible risks of routine obstetrical screening.<sup>17</sup>

## MODE OF DELIVERY

During the third trimester, new issues emerge because the fetus now is potentially viable. Care decisions address alternate modes of delivery and the option of a tertiary or quaternary care hospital to give birth. At this point physicians and patients begin to discuss the benefits of cesarean versus vaginal delivery and aggressive versus palliative care for an infant with severe anomalies, or some level of care in between. In our experience, opinions frequently vary about the appropriate route of delivery and elements of perinatal care. There is a range of reasonable values that can inform treatment options in a fetus with severe anomalies, some of which result in increased risk to the mother for the benefit of the baby; maternal autonomy should govern within this range. Fetal anomalies and genetic disorders vary greatly in severity and availability of effective treatments. The more severe the anomaly, the more important it is that the decision-making process and the language used in counseling be ethically sound.<sup>18</sup>

It is important to acknowledge the tensions between the goals of professionals and those of families. Most families are able to articulate a reasonable decision, but their preferences, values, and beliefs are sometimes discounted. Medical professionals occasionally fail to recognize extra-medical factors that include family context, physical and emotional support systems, and financial factors. Instead, professionals may prefer a more straightforward course, based upon medical indicators, or sometimes their own unrecognized personal beliefs and values.<sup>19</sup> Some physicians exert not-so-subtle pressure on women regarding the mode of delivery and care options for an infant diagnosed with anomalies such as OI and other skeletal dysplasias, aneuploidy, spina bifida, certain renal anomalies, and cardiac disorders.<sup>20</sup> The tension around these decisions may stem from the different perspectives of obstetrical careproviders and patients, as providers may focus prudently on the woman as a patient, and the woman may focus altruistically on the duality of mother and infant as patients. For example, the option to deliver in a manner that potentially minimized risk to the fetus was not acceptable to the obstetrician in this OI case.

It is possible that the unequal power/knowledge base of professionals may overwhelm the values of a woman who opts to assume the risks that a cesarean entails. Knowledge creates great power, and the increased medical and genetic complexities of delivery and care decisions may exacerbate the physician/patient imbalance.<sup>21</sup> In this construct, it is especially important that physicians acknowledge this imbalance and strive to emphasize a pregnant woman's autonomy in "life-and-death decisions" regarding her fetus. New mothers have inadequate understanding regarding the benefits and burdens of caring for an infant with severe anomalies, but, in most instances, they are in a better position than the medical community to make that assessment in their particular circumstances. Professionals may have their own opinions about the course of treatment; however, they are obligated to provide information and expertise to assist patient-centered decision making, based on the woman's own religious, ethical, and cultural values, acknowledging the completeness as well as deficits in available medical information.<sup>22</sup>

## PERINATAL CARE

Decisions about perinatal care for an infant with a severe or life-limiting anomaly can cause conflict between careproviders and families, because of some degree of uncertainty about the diagnosis and prognosis that is always present. Because medical knowledge is imperfect, choices in neonatal care are, optimally longitudinal, that is, made over time, with multiple opportunities to reassess the care plan based on new information. Therefore, professionals frequently adopt a "wait and see" approach when the viability of a fetus is difficult to predict, because even the best care plan can disintegrate when an infant's condition at birth is different from what was expected. For example, if a decision were made prior to delivery to provide only palliative care after birth, difficult questions such as feeding, providing intravenous fluids, and medications must be addressed if the baby lives days instead of hours. Such a course of action may be difficult for families and staff if palliative care training is inadequate, and care issues are not addressed prior to delivery.

The mode of delivery should not predetermine the nature of care provided after the birth of an infant with severe anomalies. A decision to offer a neonate some level of support until an assessment of his or her medical condition can be made does not necessarily mean that aggressive support or unnecessary treatment will follow. Rather, the goal may be to support the infant's life for a short time to gather more medical information after birth and enable effective grieving for the family if the infant will not ultimately survive. These reasons are sometimes unrecognized or undervalued, even when they are medically and ethically appropriate. Alternatively, on the basis of compassion, a family can decide to forego aggressive treatment because the suffering involved is too grave a burden for the infant without hope of benefit. The obligation for pregnant women and their physicians is to balance the potential benefit versus the suffering for the infant in choosing a course of treatment or palliative care. In the OI case under discussion, intervention would be indicated when it would be beneficial, useful, and not disproportionately burdensome for the infant. It would be a mistake to extrapolate this discussion to presume that aggressive treatment is always indicated; refusal of aggressive treatment in cases involving severe anomalies is often an ethical option.

### ETHICAL IMPLICATIONS

In assessing the ethical implications of this case, two medical ethics principles predominate: autonomy and beneficence. These principles are relevant based upon an accurate evaluation of the clinical facts with regard to the mode of delivery and plans for perinatal care, together with the goals of the patient. The principles of beneficence and autonomy are *prima facie* principles, which mean that they hold as long as there are no overriding considerations to the contrary.<sup>23</sup>

#### BENEFACTENCE

The principle of beneficence in clinical practice obligates physicians to strive to maximize benefit and minimize harm for their patients.<sup>24</sup> Benefit should be defined expansively to include the protection and promotion of the health-related interests of the pregnant woman and her fetus as well as extra-medical benefits.<sup>25</sup> In contrast, harm is disregard for her health-related interests and well-being. The prospective assessment of benefit is especially complex in this case due to the difficulty of making accurate predictions of good and harmful outcomes and assessing which consequences have greater weight.<sup>26</sup> According to the historical view, beneficence was characterized from the physician's perspective.<sup>27</sup> In recent times, patient-oriented theorists have reconstructed beneficence from the patient's perspective, averting the potential conflict between beneficence and autonomy.<sup>28</sup> In most clinical situations, a collaborative approach to the characterization of beneficence that takes into account the medical knowledge of the physician and the goals of the patient is most advantageous, even though this practice may need to include a way to resolve the differing perspectives.

Based on medical factors and the principle of beneficence, an urgent cesarean section is routinely advised in the case of fetal distress to benefit the fetus, even though there is some risk of harm to the woman. Likewise, an urgent cesarean section is routinely advised to benefit a pregnant woman, in instances such as severe preeclampsia, even if this would result in some harm to the fetus. When cesarean delivery poses potential risk to a woman, and the impact of mode of delivery for the fetus is neutral, vaginal delivery is recommended. In the case of a pregnancy that is complicated by severe fetal anomaly, a woman may be advised against cesarean delivery because of potential harm to her and the possible subsequent demise of the baby. Nevertheless, maternal autonomy sometimes expresses choices that may result in increased risk to self for the sake of the infant. Therefore, if cesarean delivery entails minimal risk to the woman, while the impact on the fetus is potentially beneficial, the woman's wishes regarding the mode of delivery should be respected, even if the newborn may subsequently die.

Ample data show that decision making about cesarean delivery is complex, and is influenced by a patient's preference as well as non-obstetrical factors and physicians' preferences.<sup>29</sup> The percentage of all births by cesarean section was 27.1 percent in 2003, and has been increasing over the past decade, as indica-

tions for cesarean section appear to be changing.<sup>30</sup> The physician in the OI case advised against cesarean section for a fetus with severe anomalies; other obstetricians may support cesarean delivery to potentially benefit the fetus or simply on maternal request.<sup>31</sup> For example, in the past, similar arguments were made with regard to cesarean section for myelomeningocele, a spinal defect conferring risks of paraplegia and other disability. It is now the standard recommended practice to deliver infants with myelomeningocele by cesarean section, as this is now known to provide some benefit to affected infants. Thus, as medical science progresses, recommendations regarding the mode of delivery can change.

## AUTONOMY

The ethical principle of autonomy obligates healthcare professionals to respect a patient's decisions regarding which clinical strategies she will authorize based on an evaluation of the medical indications and her values and beliefs. One important way that respect for autonomy is implemented clinically is the process of informed consent for treatment decisions. Informed consent requires a professional to disclose information in simple language, assess a patient's capacity, appraise a patient's understanding, and ensure that the decisions made are voluntary. The purpose of informed consent is to assure educated, uncoerced choice on the part of the patient. Attention to this process fulfills the ethical mandate to treat "all others never merely as a means, but always at the same time as an end in himself."<sup>32</sup> By that is meant, respect others as persons who choose their own goals, rather than merely as a means to another's end.

In contrast, a failure to provide information that a patient can understand or the exercise of undue influence from professionals or others undermines a pregnant woman's autonomy, because it thwarts her freedom to make decisions about treatment for herself and her fetus during pregnancy and delivery. Sometimes physicians truncate the norms of disclosure and respectful discussion in the process of informed consent when the prognosis is uncertain, despite evidence that patients want information even if it causes anxiety or distress. In cases such as this one, professionals may avoid adequate disclosure because they fear it could cause mistrust and confusion for the patient and the staff. Moreover, the unknowns surrounding the actual severity of the OI diagnosis and the prognosis for viability in this case made the requirements of disclosure in the informed consent process particularly challenging. However, it was precisely because the outcome was so uncertain that the physician's obligation to present information in a relevant and understandable manner was of heightened importance.<sup>33</sup>

By virtue of her condition, a pregnant woman is typically not a model of an autonomous patient (a self-governing agent/decision maker who is unencumbered by outside influences). She faces the usual impediments to the strict notion of autonomy that can include the web of interpersonal relationships, the role of community values, financial issues, legal precedents, the imbalance of knowledge and power, and other personal considerations. As a pregnant woman, she faces the additional consideration of the existence of her fetus as a second patient, who experiences the unavoidable effects of her decisions.<sup>34</sup> In this case, there were two patients, the pregnant woman and the fetus, both of whom had health-related interests and elicit ethical obligations. However, only the pregnant woman had autonomy-based obligations, and she made decisions for herself and the fetus.<sup>35</sup> Access to the fetus was only through her, and her autonomy would prevail, with limited medical or legal exceptions, as discussed below, or unless she was compromised in a way that undermined her autonomy. Professionals should assume that adult pregnant women have decision-making capacity to choose the clinical strategies that correspond to their well-being, unless there is reliable evidence to the contrary. Given this woman's situation, one would expect the healthcare professionals would work to underscore her autonomy, rather than challenge it.

The four main normative principles of bioethics (autonomy, beneficence, nonmaleficence, and justice) are intentionally unranked. Even though the principles have no assigned weight, autonomy often outweighs the others.<sup>36</sup> The frequent predominance of autonomy is relatively recent; its emergence as "first among equals" tempers the age-old belief that a doctor's primary obligation is to the principles of nonmaleficence and beneficence, and the pursuit of those principles should supersede patient's preferences and decision-

making rights when the doctor and the patient disagree.<sup>37</sup> Given the current lofty ethical and legal emphasis on patients' autonomy, it is curious that in this case the pregnant woman, who wanted to put herself at risk to potentially benefit her fetus with a severe anomaly, was questioned. The reluctance to respect autonomy is particularly remarkable in this case because such a decision was within the realm of standard of care, and there was evidence that it was well-supported by obstetrical codes of ethics and legal precedent.<sup>38</sup> Why did autonomy not rule here?

The ethical considerations in this case were seemingly broader than the principle of respect for the pregnant woman's autonomy to decide what health risk was reasonable for her to assume, to potentially benefit her fetus who had severe anomalies. In addition, this case likely entailed a patient-physician discrepancy of perspective on the value of the fetus. The physician apparently felt that the status of the fetus didn't warrant the risk of a cesarean section, and the woman disagreed. Other healthcare professionals involved in the case were uncomfortable considering quality of life issues, given the uncertainty of the severity of the OI in the prenatal diagnosis and the discrepancy of the physician's and patient's views. The pregnant woman's beliefs concerning the moral value of her fetus could not be discounted. Many pregnant women believe that their fetus possesses moral worth, regardless of a diagnosis of disability, and they make choices accordingly.<sup>39</sup> The bond that develops between a pregnant woman and her unborn child during the course of gestation is often unrelated to the medical status of the fetus. In contrast, obstetricians may hold different beliefs from patients, and focus primarily on the health of the pregnant woman and pay less attention to the potential for fetal benefit, particularly if they anticipate the fetus will die during or after birth. Ultimately, the definitive decisions regarding outcome and management of the pregnancy are the responsibility of the pregnant woman. If a physician opposes a care plan based on his or her own values and beliefs, the physician may withdraw from the case as long as the patient is not abandoned.

## LEGAL IMPLICATIONS

A review of the legal actions that address pregnant women's choices at the time of delivery are beyond the purview of this article. However, we will digress briefly to consider one recent case as an example of the potential for legal action by the state to affect maternal autonomy. Ethically, a woman can refuse a cesarean section for fetal benefit or for her own health-related interests on the basis of autonomy and clinical uncertainty.<sup>40</sup> In 2004, Utah challenged the legal right of a pregnant woman to make decisions on behalf of herself and her unborn children. The Utah court charged a woman with the death of her stillborn fetus when she declined the advice of her physicians to undergo a cesarean section to optimize the outcome for her twins.<sup>41</sup> Even though she subsequently agreed to the surgery, only one twin survived, and the prosecution alleged that the demise of the second resulted from the delay. The woman avoided a homicide charge by pleading guilty to child endangerment charges. The Utah case ignored an earlier ruling by the District of Columbia Court of Appeals, with the American College of Obstetrics and Gynecology as *amicus curiae*, that held, "in virtually all cases the question of what is to be done is to be decided by the patient — the pregnant woman — on behalf of herself and her fetus," and in the case of incompetency, the decision is to be made on the basis of substituted judgment.<sup>42</sup>

Several other states have extended their child welfare laws to address prenatal abuse or neglect. The laws vary considerably in their scope and approach, but they all mainly focus on substance abuse in pregnant women. Moreover, the fundamental nature of these legislative attempts is the same. Policy makers and law makers are endeavoring to weigh the autonomy and bodily integrity of pregnant women with society's interest in promoting the birth of healthy children.<sup>43</sup> In each instance, the legislation raises ethical questions whether: (1) the state is warranted in intervening in the private autonomous choices of pregnant woman in order to generate healthy outcomes for women and children; and (2) if punitive approaches generally foster or hinder those outcomes. In addition, the abuse and neglect language in these laws is potentially applicable to decision making in pregnancies that involve lethal anomalies, and the ensuing clinical and ethical implications for maternal choices involving life-and-death decisions could be significant.

## CONCLUSION

The woman delivered her baby via cesarean section at 38 weeks, and the baby survived for several days. During that period, additional x-rays confirmed the severity of the OI and palliative care was recommended. After the infant died, the woman reported that the opportunity to resolve the uncertainty of the diagnosis and have time to hold her baby and say good-bye was valuable. Even though the surgery likely relegated her to future cesarean sections, that didn't negate the benefit for the woman of closure and, also, the feeling that she had done everything appropriate for her infant.

By virtue of their specialized role in healthcare, obstetricians and neonatologists regularly participate in complex and difficult decisions that address issues of life and death. These decisions are complicated by the preferences of patients or their families who may have dissimilar values and different levels of understanding of what congenital anomalies can mean for themselves and their infant.<sup>44</sup> Medical decision making in pregnancies that are complicated by severe fetal anomaly requires comprehensive assessment of the quality of medical information available about the anomaly as well as the uncertainties and ambiguities in the diagnosis. In seeking a collaborative approach about pregnancy and delivery options, physicians have an obligation to foster patients' autonomy and respect reasonable maternal choices and goals that are within appropriate standards of medical care. In some circumstances, a pregnant woman's choice may include interventions that have potential benefit for the fetus, despite some negative health consequences for the mother, so that a decision may be made over time, including postnatal assessment of the baby's medical condition. A comprehensive approach to obstetrical counseling, including addressing elements of perinatal care and personal values, should be an integral part of the patient/professional relationship.

## ACKNOWLEDGMENTS

The authors would like to acknowledge the thoughtful contributions of Jacqueline Glover, PhD, Sterling McColgin, MD, and Jean Abbott, MD, in the development of this article.

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