Home Birth of Infants with Anticipated Congenital Anomalies: A Case Study and Ethical Analysis of Careproviders’ Obligations

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ABSTRACT

This article presents the case of a mother who is planning a home birth with a midwife with the shared knowledge that the fetus would have congenital anomalies of unknown severity. We discuss the right of women to choose home birth, the caregivers’ duty to the infant, and the careproviders’ dilemma about how to respond to this request. The ethical duties of concerned careproviders are explored and reframed as professional obligations to the mother, infant, and their profession at large. Recommendations are offered based on this case in order to clarify the considerations surrounding not only home birth of a fetus with anticipated anomalies, but also to address the ethical obligations of caregivers who must navigate the unique tension between respecting the mother’s wishes and the duty of the careproviders to deliver optimal care.

INTRODUCTION

We present a case that addresses the unique ethical considerations for clinicians serving patients seeking home birth for infants with anticipated congenital anomalies. The case depicts the contours of maternal rights, fetal and infant rights, and careproviders’ obligations. In this scenario, fetal abnormalities were detected on an early series of routine prenatal tests and the mother declined any further testing, while remaining committed to her plan to deliver her infant at home. Facing the dilemma between respecting the mother’s autonomy and ensuring the safest passage for the infant, as well as honoring their own professional obligations, the careproviders sought consultation with a clinical ethics consultation service. Although recommendations were offered to the physician who requested the ethics consult, upon later reflection, we felt perhaps we had missed some opportunities to better mediate this situation.

In hindsight, perhaps we failed to fully understand the implications of the case and the obligations of the careproviders involved, and could have been more effective if we had met with parents in person, rather than offering recommendations to the clinical careproviders. We did offer to meet with the parents and the midwife, but neither wished to do so. Although the case has since resolved, there is a lingering sense that more could have been done to reduce the moral distress experienced by the careproviders, and to better clarify their duties to the patient and the fetus. As a retrospective single case review, we present the tensions that emerged in this
scenario as a way to reconsider the case and press beyond what was offered at the time, in order to explore recommendations for the ethical management of uncertain infant outcomes when home birth is desired.

THE CASE STORY

Pregnant with her second child, Mara and her husband Mark (pseudonyms) are receiving care from a midwife who helped with the uncomplicated pregnancy and delivery of their first child at home two years ago. Joanna, a certified nurse midwife (CNM), orders an ultrasound when Mara reaches 20 weeks’ gestation and the findings include what appears to be a constellation of fetal abnormalities. Joanna refers the couple to a maternal-fetal medicine specialist at a nearby academic tertiary care center for further testing. Amniocentesis confirms trisomy 21 (Down syndrome) and, a couple weeks later, a level-3 ultrasound indicates that the male fetus has an absent corpus callosum and asymmetrical cardiac ventricles.

The obstetrician is unable to clearly define the extent of the cardiac defect and the couple is strongly encouraged to follow up with a pediatric cardiologist to clarify what appears to be a serious cardiac anomaly. The obstetrician offers the couple the option to terminate the pregnancy. Mara and Mark decline further testing.

They tell their midwife that rather than hear more bad news or be pressured to change their minds about a home birth, they prefer to continue with their plan to deliver the baby at home and prepare to accept that he will not live long. Steadfast in their commitment to a home birth plan, Mara and Mark contact a funeral home and prepare for the baby’s death. Joanna, the midwife, reaches out to the hospital’s palliative care service for professional advice and support in managing the anticipated perinatal death shortly after delivery.

But there are lingering questions in the absence of further information about the fetus’s prognosis related to his fetal heart defect. It is quite possible that the baby does not have a fatal anomaly, but a repairable defect, or one that is survivable with no urgent need for intervention. The pediatric palliative care physician contacts the ethics consultation team for help in determining how to best assist the midwife and the couple. That is, the palliative care physician questioned whether it was appropriate for Joanna to be involved in this birth when the prognosis for the newborn was unsettled, and the neonate might need resuscitative care, rather than palliative care, depending upon the severity of the cardiac abnormality.

It is important to note that the ethics consultation was only directed at this question posed by the palliative care pediatrician, even though our discussions here address the broader questions raised by the case.

THE RIGHT TO CHOOSE HOME BIRTH

The authors, a clinical bioethicist and a bioethicist who is also a obstetrician/gynecologist, support the right to home birth in principle, but believe that aspects of this case fall outside the parameters in which home birth is acceptable, even for advocates of home birth. The safety of home birth, even in low risk pregnancies, remains a disputed issue, with two meta-analyses reaching opposite conclusions. Ultimately, the question of safety is irrelevant to the ethics of this case for two reasons. The first is that this is not a “low risk pregnancy,” and a fetus with cardiac anomalies is best delivered in a tertiary care hospital, where intensive care facilities exist should the baby need immediate surgery or medical therapy. From the perspective of the fetus as a patient, a clear beneficence-based argument can be made against home birth in this case. The second reason is that although Mara is not unconcerned about her infant, the setting of her birth is a primary concern for her, and she is adamantly opposed to going to a hospital because she fears that medical care providers will not listen to her wishes regarding the birth and postnatal treatment of her baby. She chooses a home birth despite the medical issues her child may face after birth. Furthermore, she seems to have reached her own conclusions about his prognosis, even though the physicians involved in her care have not yet made a firm diagnosis of his cardiac anomalies. It is clear that Mara’s focus is on the need to prepare for the death of her infant, rather than on his possible requirement for intensive care.

This case can be understood as one of maternal-fetal conflict because Mara desires a home birth and her fetus is best served by a hospital birth. The American College of Obstetrics and Gynecology (ACOG) is unequivocal in its position regarding maternal-fetal conflict. While women must receive accurate and complete information regarding their choices and the risks, benefits, and consequences of their choices, maternal autonomy must never be overridden when there is a clear fetal harm incurred by the mother's choice. In this case, there is only a risk of harm because the fetal prognosis is uncertain. While physicians have a duty to fetal benefi-
cence for pregnancies that are beyond viability (24 weeks), this duty can only be fulfilled with maternal consent. In this case, prenatal tests indicate fetal anomalies but no clearly fatal diagnoses, and the mother chooses to reject the recommended tests that can provide more precise information. From the clinician’s perspective, there is an irresolvable tension between the desire to support beneficence-based obligations to the fetus and the need to uphold the mother’s autonomous choice to refuse further testing.

While some argue that maternal autonomy can be overridden for fetal benefit, the law clearly sides with the autonomy of the patient in these circumstances, as the court opinion in the Angela Carder case shows. Angela Carder was a woman dying of cancer who refused a cesarean section for her extremely preterm fetus, arguing that neither she nor the fetus was likely to survive the surgery. Her decision was overridden by a local judge, and the cesarean section was performed: both Angela and the baby died a short time later. Using rights-based reasoning, the appellate court argued that it could not “imagine” a circumstance in which maternal choice could be overruled for the benefit of a fetus. A woman’s right to bodily integrity and privacy outweigh the fetal right to live, even beyond viability. Surgery is one of the most physically invasive things that one person can do to another, and must only occur with valid and informed consent.

Heather Draper, a philosopher and ethicist, argues that while a woman does have an ethical obligation to her unborn fetus, this duty can never be compelled, because such compulsion could lead to other restrictions on women’s freedom, and its application would place undue burden on women. Draper further argues that it is a gross simplification to view a pregnant woman’s decisions as a threat to her fetus that can be overridden by a forced choice regarding birthing, because most of the harms that can befall a fetus are related to societal ills and social inequalities, which are beyond the means of a pregnant woman to repair. Thus, society holds a pregnant woman responsible when it is the duty of the community to do so, and child welfare that is neglected. Coercive action against pregnant women merely shifts blame in the wrong direction.

This reasoning against forced cesarean section is easily extended to Mara’s decision to remain at home for the birth, despite the possible risk to the fetus. Although an ethical argument could be made that a woman, having chosen to become pregnant and remain pregnant beyond viability, now owes an ethical duty to her fetus to keep it safe from harm, this is a duty that a healthcare provider has no right or power to compel.

A strong consequentialist argument can be made against overriding maternal autonomy. If physicians and midwives are charged with enforcing testing and interventions with patients in such cases as this one, a woman may see her obstetrician as a potential adversary should their choices and values not align. This would have damaging effects on the physician-patient relationship. As it now stands, physicians are encouraged to present all sides of choices to their patients, but patients should feel secure that their choices will remain within their control. The law now sides with this view, and the patient in this case retains the right to deliver her baby in the setting and with the careprovider of her choice, regardless of the potential risk to the baby.

THE CAREPROVIDERS’ DUTY TO THE INFANT

Given the medical uncertainties surrounding the extent of the fetus’s abnormalities, this case challenges careproviders to consider their professional obligations to the baby once he is born. The mother retains full autonomy for herself and the fetus prior to delivery; however, the baby becomes a separate patient once he is born, and careproviders have a duty to the infant that is distinct from their obligations to the mother. For the birth attendant, the limited information about the fetus’s congenital anomalies hampers her ability to prepare for the birth. The Baby Doe Amendment limited decisions to withhold or withdraw medical treatment from disabled infants less than one year old. These federal regulations, promulgated in 1985, require that disabled infants with life-threatening conditions receive the “appropriate nutrition, hydration, and medication which, in the treating physician’s . . . reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions . . .”

This legislation also accommodates situations in which treatment would not be effective and would merely prolong dying, and allows that, when an intervention would be futile or nearly futile, there is no obligation to initiate life-sustaining treatment. Mara and Mark’s preference for a peaceful delivery and natural death for their newborn would be permissible, should the medical facts indicate that the baby’s medical conditions were irreversible and treatment would be futile or otherwise inhumane.

The parents’ refusal to complete the recommended prenatal testing does not allow a fully informed decision to be made. In the absence of this
knowledge, the midwife and consulting physicians will need to make a clinical judgment after delivery regarding whether or not the baby’s condition satisfies the standard for withholding life-sustaining treatment. The careproviders and the parents are ethically and legally obligated to seek prompt evaluation if the baby’s condition suggests he is capable of survival. Without knowledge that might confirm the baby’s prognosis, the decision about any intervention is postponed until his birth. Once he is born alive, the infant may not be denied access to medical evaluation and appropriate medical care, even over the objection of the parents, unless he has a clearly fatal condition.

THE CAREPROVIDERS’ DILEMMA

Although the Baby Doe Amendment provides direction for careproviders once a baby is born, the midwife and consulting physicians engaged in this case are left with very little information about what the baby’s condition will be at delivery, because no further testing has been done. Despite our requests to speak to Mara directly, she would not meet in person or by phone with the clinical ethics consultants. We presume our recommendations were shared with Mara and Mark by the midwife, who does have communication with the palliative care physician regarding our recommendations.

After her initial ultrasound with the obstetrician, Mara does not return to this physician, nor does she follow up with the pediatric cardiologist, as we recommended. Given the constellation of known abnormalities, there is good reason for concern, but just how much concern is unclear—paradoxically creating even more worry for the careproviders. In stark contrast to the literature, which urges expediency in completing testing and communicating prenatal findings,9 Mara asks her careproviders to do the opposite. For her, more testing equates to more bad news, and she fears a challenge to her decision to have a home birth, although the ethics consultants assure the consulting careproviders that the choice to deliver at home is not threatened by a more complete prenatal diagnosis. Because the patient is exercising her autonomous right to refuse further medical testing, the midwife is left to make clinical decisions about the welfare of the baby at the time of delivery with incomplete knowledge.

For the midwife attending the home birth there are a number of ways the case may unfold. First, the baby could be stillborn in which case no medical intervention is appropriate, nor would transfer to a medical center be warranted. A second possibility is that the baby is born alive, but with a presentation that suggests his condition is not survivable. In this scenario, palliation without transfer would be acceptable to allow for a natural death—but midwives do not have the kind of specialized knowledge that allows this kind of judgment without immediate consultation, so it is hard to imagine a scenario in which the midwife can confidently make this decision. A third possibility is that the baby is born in a condition in which his medical needs are unclear, but there is some evidence of neonatal compromise. The midwife is then obligated to seek emergency medical evaluation, perhaps calling an ambulance, even over the objection of the parents if they do not consent. A fourth possibility is that the infant is born with no observable urgent needs, and the parents seek medical evaluation and follow up within a reasonable time, or as a need arises.

The pediatric palliative physician consulted by the midwife shares similarly complex obligations. As a pediatrician with expertise in pediatric palliative medicine, the role of this careprovider is to assure safe and effective symptom management for patients with chronic or life-limiting illness. If it is known with reasonable certainty that a baby has a congenital defect that is incompatible with life, there is a clear role for a palliative careprovider: to assure that any suffering for the baby is minimized, and that the baby’s death is as peaceful and supported as possible, as is the parents’ preference.

Palliative care is frequently provided for patients outside the hospital, and providing palliative care in the home setting is not problematic, except for the medical uncertainties. Navigating how best to serve an infant who may be born alive but in need of emergent intervention places this pediatrician in a position alongside the midwife, with the same obligations under the Baby Doe regulations. A request for palliative care at a home birth stretches the boundaries for this careprovider because home birth is not considered safe when there is concern about the well-being of the baby upon delivery. In this setting, the pediatrician is unable to assure that the best medical care can be provided to the infant, and the doctor hesitates to participate in this case, despite knowing she might be able to offer a valuable postnatal assessment.

RECOMMENDATIONS

The rights and interests of the mother and fetus, although uniquely intertwined, must be considered carefully and distinctly. Given that the mother has the right to make an autonomous decision to deliver
her baby in the setting and with the careprovider of her choosing, the home delivery aspect of this case does not represent an ethical dilemma, although careproviders may feel some moral regret about being unable to pursue a course that is most beneficial for the fetus. The ability of the careprovider to assure that the expressed preferences of the couple for postnatal care are honored is significantly hampered by their refusal to seek further prenatal testing. In the absence of testing to confirm the lethality of the baby’s multiple medical problems, the parents may very likely end up losing the authority to decline emergent medical interventions for their baby if he is born alive and ill, because the birth attendant will be obligated to seek prompt evaluation. Our recommendation is that Mara undergo the advised prenatal testing to confirm the infant’s prognosis. Although this is not her preference, this information will enhance her ability to make informed decisions for herself and her infant, and could clarify whether the palliative care physician, who initially requested the consult, has an appropriate role to play in the child’s life.

We advise the physician that she does not have a prima facie duty to the mother or infant and is not obligated to attend the birth. As a palliative care pediatrician, she is not fully trained to assess, diagnosis, and stabilize a newborn at home with a cardiac defect. She is, in essence, being asked to practice outside her specialty. We further clarify that should she elect to attend the birth, she is bound by the same obligations as the midwife in seeking emergent medical evaluation, if indicated.

OUTCOME

Despite our recommendations to the careproviders, the case record indicates that Mara and Mark did not seek any prenatal testing beyond the routine care provided by their midwife. We were later advised that Mara delivered a male infant at home with the midwife attending the birth. The palliative care physician did not attend the birth or care for the child after his birth. The infant was observed to be in stable condition and was not taken for evaluation until a week later, when he showed some signs of cyanosis (blue or purple coloration due to low oxygen saturation). Mara and Mark brought the baby to a tertiary care center, and he was admitted to the neonatal intensive care unit and found to have a repairable cardiac defect. The parents readily consented to the lifesaving cardiac surgery. Following a successful operation and recovery, the baby returned home with his parents and sibling.

REFRAMING THE QUESTION

Although this consultation was requested by the palliative care physician, who wondered whether she had an appropriate role in the care of the soon-to-be-born-at-home neonate with a cardiac defect and uncertain neonatal prognosis, we now believe we missed at least one important ethical dimension of this case: the professional obligations of the midwife. Midwives are supposed to provide care for low risk pregnancies, particularly for home births. Although Frank Chervenak has argued that physicians should never support home birth, we believe the arguments made against this position recently in this journal are more compelling. Jeffery Eckers and Howard Minkoff responded to this position by re-examining the data and concluding that the small, unproven, additional relative risk of home birth is trivial when translated into absolute risk, and that women and physicians can responsibly choose and participate in home birth within the preconditions of experienced midwives and low risk women. It was the known defects, of uncertain lethality, that pushed us to argue against an appropriate professional role in supporting this home birth. Once it became clear that the nature and extent of the risks to the fetus would remain undefined—and might include a baby who was immediately cyanotic at birth and urgently required intensive care—we believe the midwife was acting outside the scope of her practice in continuing to provide care and allowing the home birth to proceed under her supervision.

Joanna would not be justified in continuing to provide care, even if her refusal meant that Mara would find a less-skilled or unskilled birth attendant. Careproviders are obligated to define the boundaries of practice for patients, but careproviders cannot be compelled by patients’ assertion of their positive right for care that is beyond the careproviders’ skill set. To do so, in violation of professional standards, out of a fear that patients will fare even worse if their requests are refused, is a misapplication of the principle of beneficence.

On the other hand, while it is a professionally sound practice for careproviders to not provide care that falls beyond their skill set, it could be argued that declining to provide requested home birth services will not lead to the desired outcome—in this case, that the patient will choose to follow medical recommendations. Thus, even a well-considered, beneficence-driven decision to decline to provide further care may not have resulted in a better outcome for the mother and infant. One concern may
be that refusing to continue to provide services to this mother would have constituted abandonment. But legally, abandonment would only be present if the midwife failed to make timely and appropriate referrals for continued care. This does not seem likely in this case, because there is plenty of time for the midwife to give notice to her patient and for the mother to find an alternate careprovider.

A second argument against withdrawing from the case is that the mother will perceive being dismissed by the midwife as an act of abandonment or coercion and respond by foregoing medical care for herself and her infant altogether, including her delivery. Should the mother elect an unattended birth at home, she and her baby may be at greater risk than they would be by having a less skilled careprovider present. Given this mother’s clear disdain for further prenatal diagnostic testing, it is not unrealistic to fear she might pull away from all birthing assistance. This creates a compelling professional dilemma for the midwife, who may decide her being present is better than Mara having no birth attendant at all. But this response would be speculative and fear-driven. To fail to engage in a frank discussion about the limitations of midwifery in this scenario does not enhance the mother’s autonomy or assure a good outcome for her and her infant.

These possible scenarios, while concerning, do not outweigh a careprovider’s professional obligation to recognize her own limitations and act accordingly. To practice outside of one’s skills and ability is to provide negligent care, and this could never be justified by the fear of what a patient may choose to do when the careprovider refuses to provide care outside her or his scope of practice. Although a careprovider’s concerns that withdrawing from the case may create an even greater risk of harm, that would not be the careprovider’s intent—and there are alternatives.

One alternative would be to arrange for a hospital delivery with a well-defined birth plan. Another alternative would be to find a pediatrician willing to attend the delivery who is skilled in neonatal resuscitation and cardiac assessment. But there are problems with both alternatives. First, since home birth is supposed to be limited to low risk births, there is no precedent for this level of neonatal care in the home birth setting. Second, the equipment necessary for this kind of intervention is extensive and not readily transported to a home setting.

The American Academy of Pediatrics (AAP), like the American College of Obstetricians and Gynecologists (ACOG), favors hospitalized birth for all patients, but specifically recommends against home birth in the presence of maternal or fetal disease such as the anomalies in this case. Regardless of the parameters defined by AAP and ACOG, it could be argued that, in some cases, a physician may feel a duty to intervene even in a suboptimal setting, and there might be a supererogatory duty to the fetus that supersedes the general boundaries established by contemporary AAP and ACOG guidelines. Pediatricians who feel morally compelled to provide medical evaluation and intervention beyond the walls of the hospital ought not to be prohibited from doing so, provided there is sufficient expectation of benefit justifying the exception. In cases when it is expected that the intervention required is low risk, or when there are other barriers to prompt medical attention, a stronger case can be made to stretch the boundaries of standard practice. An example of a low risk would be a postdate pregnancy (a pregnancy that has continued past the expected due date), in which the risk of meconium (a fetal bowel movement into the amniotic fluid) and respiratory complications is higher. In such a case, the risk is marginally higher than a term pregnancy, but the necessary equipment to improve safety at the birth is more manageable than it would be for Mara and Mark.

More formidable barriers to prompt medical intervention, such as extreme poverty, distance to a medical facility, lack of transportation, or lack of a telephone to call for help, may increase a careprovider’s duty to attend to a patient in the home. The coordination required to bring a pediatrician to the bedside could perhaps be better applied to planning for the mother to come to a hospital instead, but we acknowledge there may be exceptional cases. In an emergency, such as a precipitous delivery in public, a pediatrician may elect to assist as a Good Samaritan, and accept the risks inherent to delivering without standard resources on hand. In these instances, some help, although not ideal, may be better than no help at all.

Mara and Mark’s midwife contacted a palliative care physician for possible assistance at the home delivery. The palliative care physician had often and routinely planned and provided care in the home setting when it served her patients’ best interest. If Mara and Mark knew with reasonable certainty that their fetus had a defect that was incompatible with life, the pediatric palliative care physician would have been willing to attend the delivery to provide appropriate end-of-life care. The uncertainty was whether the baby would require palliative care or intensive care. Even though the palliative care physician would attend a child at home, this does not obligate her to provide home-based care that would
fall outside the parameters of her professional abilities. A palliative care physician is not trained to manage cardiac anomalies in a newborn, and the doctors who would be capable—neonatologists and pediatric cardiologists—do not typically practice outside the hospital setting, in part because the benefits of their expertise rests in the complex technology required to perform their duties. The palliative care pediatrician faces the same concern as the midwife: practicing outside her skill set.

No ethical duty to attend the birth exists in this case because, given the mother’s choices, the risks could not be effectively mitigated, and there were alternatives she would not consider. The parents chose not to allow an adequate workup to determine the severity of the fetus’s cardiac lesion. The risk in this setting was not only the fetal anomaly, but the lack of information secondary to the patient’s preferences. This was a planned event, with an anticipated need for additional care, yet the mother requested no assistance beyond the midwife, because she believed the outcome of neonatal death was inevitable, even though the medical team thought otherwise—and subsequent events proved the mother wrong. The family lives 15 minutes from a tertiary care center that has adequate resources. Mara’s decision to avoid a hospital birth was based on her moral beliefs and preferences, and she reached conclusions that were not supported by facts. Her choice to avoid even non-invasive prenatal testing and her commitment to an out-of-hospital setting suggest that an offer to bring high-tech equipment to her home—if such a farfetched option existed—would have been refused. The situation did not present a scenario that generated a sense of clear benefit, urgency, or concern that might otherwise persuade a physician to stretch the boundaries of his or her practice.

As Kant is often paraphrased, ought implies can, and because there was no reason to have confidence in the ability of a physician to manage all of the possible cardiac outcomes at birth, there was no reason to believe there was an ethical duty to expect a physician to put her- or himself into this circumstance. Even a fully collaborative model of care between midwives and physicians—a model not currently extant—would not resolve the problem that the fetus could not be adequately cared for after birth in any setting except a tertiary care hospital. A pediatrician’s presence or absence at this home birth would not alter the risks or uncertainty of the outcome for this infant upon delivery.

Patients who desire a home birth should not fear prenatal testing of their fetus. Less than 5 percent of all newborns are born with an anomaly, and many cases do not require urgent intervention. In this case, further testing would have revealed a cardiac lesion that did not require urgent intervention, and home birth would not have been judged inappropriate (and a palliative care physician’s assistance would have been unnecessary). In the rare cases when an anomaly is discovered that would benefit from immediate intensive care, the mother should choose hospital birth; but, returning to this case, the choice for hospital birth could never actually be compelled. Practically, it is possible to imagine a situation in which parents feel their choice of a birthplace is not available, because no midwife or physician would be willing to participate in a home birth choice when the pregnancy falls outside the accepted parameters of low risk care. Faced with the realization that their choice had no support from physicians or midwives, most parents would accept a hospital birth, but even if this proves not to be the case, careproviders cannot be held hostage by parents’ poor choices. Home birth providers could practice “preventive ethics” by making the parameters of their care explicit at their first visit—and many do.

Had Mara and Mark’s baby died during transport to the hospital from an otherwise survivable cardiac anomaly, the midwife could have faced negligence charges and sanction by her licensing body for practicing outside the scope of practice for licensed nurse midwives. Because we did not personally meet with the midwife in this case, this is only speculation, but midwives do form very close personal bonds with their patients, and this may have obscured this midwife’s clear vision of her professional duties and limits. Reminding practitioners that the tension between professional integrity and patients’ autonomy must sometimes lead to decisions to withdraw from a particular situation is certainly a central and recurring theme in clinical ethics. Because midwifery is a marginalized profession, most midwives will benefit when they hew closely to the guidelines and limits of their profession, and so avoid potentially preventable bad outcomes that opponents of home birth can use in attacks against it.

In one author’s experience (PB), many home birth midwives are explicit about when a transfer to hospital care would be required of the birthing couple, and parameters of this kind are generally based upon the risk status of the mother and the fetus. This conversation should, and often does, occur at the first prenatal visit when the parents and the midwife are still deciding if they will work well together as a team. To provide safe care, midwives
need to be able to tell parents that they can no longer participate in their birth because of changes in risk status. While doing this during labor would represent abandonment, doing this halfway through the pregnancy would not be abandonment, and the midwife could have used her relationship with the parents to persuade them either to define the cardiac lesion more fully or seek a hospital birth. When careproviders define clearly the limits of their skills and scope of practice, the intent is not to coerce a patient into accepting a recommendation; the intent is to remain within the parameters of safe care. A patient remains free to make her own choices, but, as careproviders, our choices must be constrained by both ethical and medical limits that must not be crossed, despite a patient’s request. In this case, the medical uncertainty creates an ethical duty. The risk to the newborn cannot be justified by the mother’s choices and desires, and nonparticipation is the only ethical option if the mother remains steadfast in her refusal for more information.

The counter argument, namely that the autonomy of the patient includes a positive right to dictate the limits of care, needs little rebuttal. If a patient’s autonomy could override physicians’ and midwives’ responsibility to remain within their respective scopes of practice, then a patient’s request to her obstetrician to provide a home cesarean section has no grounds for denial, a clearly dangerous and ethically unsupportable action. But a patient’s autonomy is generally understood to extend to a near universal right of refusal of consent, not a universal right to request procedures, particularly those which demand that physicians or midwives exceed their own medical or ethical limits. Furthermore, if what is requested is unsafe or unethical, not because of the personal limits of one careprovider but due to the nature of the request, then no duty to refer exists. In this case, Mara’s choice to birth at home cannot be made safe without additional fetal testing, and persuading her of this and refusing care if she is unmoved are the only ethical options.

Ironically, by staying with Mara in her birth, the midwife was threatening birth options for other women by opening herself, and her profession, up to criticism. This was a dangerous precedent that could have jeopardized the midwife’s professional status and the perception of her profession in the broader healthcare community.

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PERMISSIONS

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NOTES


5. Ibid.


16. Ibid.


20. AAP Pediatrics Committee on Fetus and Newborn, “Planned Home Birth,” see note 15 above.