Truth Telling and Severe Fetal Diagnosis: A Virtue Ethics Perspective
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ABSTRACT
Purpose: Increased use of prenatal technologies has increased the numbers of women and partners whose fetus is diagnosed with a severe impairment. Virtue ethics provides a useful perspective to consider truth telling in this context, specifically how couples and providers interpret the diagnosis and prognosis to create truth. Virtue ethics is person-centered rather than act-centered, with moral actions guided by how a virtuous person would act in the same circumstance. Phronesis (practical wisdom) guides these actions. Subjects and Methods: Fifteen women and 10 male partners with a severe fetal diagnosis participated in this longitudinal ethnography examining their experiences across 3 available care options: termination, routine obstetric care, and perinatal end-of-life care. Data from 39 interviews were analyzed to determine how they created meaning and truth in context of the diagnosis. Results and Conclusions: Providers’ interactions were usually, but not always, characterized by the practice of phronesis. Couples were in a more complex moral situation than were providers. Those who terminated created a socially acceptable truth within a negative social environment related to abortion. Those seeking routine care had uncertain fetal prognoses and struggled with the meanings of “odds” of survival. One couple with end-of-life care experienced a close alignment of the facts and the truth they made public.

Key words: fetal defects, prenatal diagnosis, virtue ethics

Prenatal technology and the diagnosis of a severe fetal defect have substantial ethical implications. The increasing use of prenatal testing for severe fetal defects has resulted in a similar increase in the number of women and families learning of severe diagnoses and experiencing the accompanying distress. Despite a woman’s level of risk for any specific fetal defect, maternal serum screening for defects during pregnancy has become the norm in the United States.1−3 At least two-thirds of pregnant women in the United States now have at least one ultrasound examination.4 Ultrasonography appeals to women and families as a means of seeing the developing fetus, but with little understanding that the purpose of the scan is to screen for fetal defects, they are unprepared for adverse findings.3,6

Suspicious, equivocal or positive screening results set into motion a series of events to determine whether the fetus is indeed impaired. This may include referral to a tertiary maternal-fetal setting for diagnostic testing, such as chorionic villus sampling or amniocentesis, and/or more sophisticated ultrasonography. Confirmation of the diagnosis of a fetal defect can be devastating.7 Shock and grief are common responses,8 moreover the diagnosis can pose an existential crisis because of the life-or-death choices these couples are required to make.9 The urgency of time related to legal issues surrounding termination, managing information, and the traumatic repercussions of the diagnosis characterize their experience, regardless of what the diagnosis was and whether the pregnancy was continued or terminated.9

The diagnosis of a severe fetal defect may constitute a situation with “terrible alternatives”10—termination of a wanted pregnancy, intrauterine fetal death, neonatal death, or a severely impaired infant—into which expectant couples are forced, and for which there is no good
outcome. Even the choice to pursue diagnostic testing following a suspicious or equivocal screening has moral weight, as women and families make an a priori determination about what the implications of a positive diagnosis would mean to them, and how or if they would act on this information. Furthermore, despite advances in technologies to detect fetal anomalies, little can be done to treat or correct substantial structural anomalies in utero.11

From screening through definitive diagnosis of a fetal defect, the question of truth underlies the discourse among various stakeholders: what is the truth that represents the most acceptable construction of the facts as they are known? Truth is a concept that encompasses the fact that the fetus is severely impaired, and the interpretation and constructed meaning of the diagnosis and ensuing decisions by the women and their partners. The purpose of this article is to describe the experiences of 15 women and 10 male partners as they interpreted and made meaning of the fact that their fetus was substantially impaired, with particular attention to the way facts were presented to them and how they constructed their own truth. Virtue ethics provides a useful perspective from which to examine this phenomenon.

VIRTUE ETHICS, TRUTH AND SEVERE PRENATAL DIAGNOSIS

Nurses are usually acquainted with act-centered ethical frameworks such as utilitarianism and deontology that provide principles that guide one’s approach to moral dilemmas. For instance, a person who prescribes to a utilitarian approach believes that the moral rightness of an action is determined by the consequences of that action. Telling the truth for one who subscribes to a utilitarian ethical framework means that sometimes truth may be withheld if the consequences of telling the truth may be injurious. A person who subscribes to a deontological approach believes that an individual’s duty or honoring moral obligations to another human is morally correct regardless of the consequences. The moral principle of veracity (truth telling) for a deontologist then means that one’s duty is to tell the truth, regardless of the consequences.

Virtue ethics provides an alternative to utilitarian or deontological frameworks. Virtue ethics is person-centered rather than act-centered with “right action” guided by what the virtuous person would do in the same circumstances.12 Virtues are “morally excellent character traits.”13 Begley14 described virtue as “excellence in relation to a skill or trait of character and is linked to function”; for instance, the virtuous nurse is one that performs his or her functions in manner that reflects excellence in nursing skills, theoretical knowledge and character. Furthermore, Begley15 listed an array of attributes of a virtuous character recognizable as principles (eg, justice, benevolence, integrity, faithfulness, veracity) associated with more conventional moral frameworks such as deontology. She expanded this list to include “professional virtues” such as theoretical wisdom or knowledge, competence in skills, understanding, genuineness, imagination, and perseverance.

Carnevale10 argued that virtue ethics provides a means of recognizing that some dilemmas are irresolvable tragedies with “forced terrible alternatives” that are best addressed by wisdom rather than duty or obligation. The concept of prudence, commonly associated with virtue ethics, is most simply interpreted as practical wisdom and refers to the human capacity to deliberate well and enables one to determine the right means to a good end.10 Although there is no “good” outcome in a tragedy, the outcome is not necessarily unethical when alternatives are weighed from the perspective of a phronetic person with a virtuous character, rather than deferring to simple decision-making models, such as cost-benefit ratio.10

One of the most troublesome aspects of the work of healthcare providers is sharing information that is upsetting, worrisome, or otherwise distressful to patients. From a virtue ethics perspective, virtuous providers possess prudence (practical wisdom) plus a complement of professional virtues. In the case of a severe prenatal diagnosis, this means that the wise provider recognizes his or her moral obligation to convey the bad news of a fetal defect in a way that minimizes distress to the patient. Similarly, patients in turn must determine to whom, how and to what extent they share their own interpretation of this news. Drawing on their own practical wisdom, compassion, patience and veracity, patients must determine what to do—terminate or continue the pregnancy—and, if continuing, to what extent to intervene for fetal or neonatal distress. Although this study was not specifically focused on truth telling and virtue ethics, participants’ narratives surrounding their troubled pregnancies often included spontaneous descriptions of how the facts of their situation were conveyed to them, and how these facts were subject to idiosyncratic interpretations that eventually yielded their truth.

METHODS

This article reflects the analysis of interview data collected from women and their male partners in a longitudinal ethnography, the primary purpose of which was to compare the experiences over time of 3 groups of women receiving a severe fetal diagnosis, including those electing (1) termination of pregnancy; (2) continuation of pregnancy under routine care with obstetric intervention and neonatal resuscitation; or (3) continuation of pregnancy with perinatal end-of-life care, with no obstetric intervention for fetal indications, and comfort
care (as opposed to life support measures) for live-born infants. This study was approved by a human subjects review board.

**Sample**

Purposeful sampling was directed toward achieving maximum variation in type of diagnosis, pregnancy outcome, and race/ethnicity. Women were recruited as soon as possible after diagnosis of a severe fetal defect from the maternal-fetal medicine clinic of a major tertiary care center. Enrollment of the partner was not an eligibility criterion for women’s participation, although partners were invited to participate. Consent was obtained from both partners, and consent forms in Spanish were used for Spanish-speaking participants.

**Data collection**

Digitally recorded interviews lasting about 1 hour were conducted in participants’ homes. Each interview started with a broad question; follow-up questions were used to clarify responses and probe for further details. The first interview focused the pregnancy, diagnosis, and decision to continue or terminate the pregnancy. The second interview occurred near the due date (regardless of whether the pregnancy was continued or terminated), and focused on details of events at the end of pregnancy. The third interview, scheduled midway between the due date and 1-year anniversary of the diagnosis, focused on participants’ current view of their decision regarding continuing or terminating the pregnancy. The final interview was 1 year after diagnosis, and participants reflected on the previous year and to describe their future plans.

**Data analysis**

Interviews were transcribed verbatim. Field notes detailed elements of the setting and documented participants’ demeanor and emotional responses unavailable by audiorecording. Two women and the husband of one who were Spanish-speaking were interviewed twice with a professional interpreter using consecutive interpretation, a technique in which the interpreter waits for the interviewer to complete a question before addressing the participant. In turn, the participant gives a complete response before interpretation is initiated. An independent translator translated the Spanish transcription into English; no inconsistencies were discerned between the interpreter and translator.

Particular attention was paid to how participants talked about the diagnosis, prognosis, how they learned about the diagnosis and prognosis from providers, who and how they were told about the fetal problem and how they talked about the way the pregnancy ended. This also included their beliefs about the fetal problem and how they managed providers’ rendering of “odds” related to fetal or infant survival. Interactions between the participant and other(s) were coded for content and how the participant interpreted the interaction. Evidence of euphemisms, evolution and/or change of their story in response to the persons involved in the interactions was recorded (eg, referring to termination as miscarriage to friends but not family). In addition, participants’ spontaneous assessments of the interaction were noted (eg, “she was rude”).

Data matrices were constructed that compared women and partners, women with differing diagnoses and women across the 3 care options. These matrices yielded significant descriptive data of how participants interpreted and made meaning of the facts of the fetal diagnosis and the ensuing decisions, and how they created their version of truth related to this distressing event in their lives. Trustworthiness was insured by prolonged engagement with participants, which allowed the investigator to summarize and paraphrase the participant’s experience during each and at subsequent contacts.

**FINDINGS**

Fifteen women and 10 of their male partners participated in this study and were interviewed from 1 to 4 times over a year (Table 1).

Military deployment resulted in the withdrawal of 3 couples. An additional couple separated and the partner moved out of state, whereas another 2 couples and 2 women were lost to follow-up before sampling and data collection were complete. This constitutes the main limitation of this analysis. There were 8 different fetal diagnoses, with 4 having significant comorbidities (Table 2).

<table>
<thead>
<tr>
<th>Table 1. Demographic Data</th>
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<tbody>
<tr>
<td><strong>Women (n = 15)</strong></td>
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<tr>
<td><strong>Age</strong></td>
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<tr>
<td>(range 18–40)</td>
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<tr>
<td><strong>Race/ethnicity</strong></td>
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<tr>
<td>Black 3</td>
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<tr>
<td>Hispanic 3</td>
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<tr>
<td><strong>Married</strong></td>
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<td><strong>Education, y</strong></td>
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<td>(range 2–18)</td>
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<tr>
<td><strong>Household income (USD)</strong></td>
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Table 2. Fetal Diagnoses and Pregnancy Outcomes

<table>
<thead>
<tr>
<th>Diagnoses</th>
<th>n</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Diaphragmatic hernia</td>
<td>3</td>
<td>1 with Trisomy 13, 1 with Chromosome 8 deletion</td>
</tr>
<tr>
<td>Renal agenesis</td>
<td>3</td>
<td></td>
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<tr>
<td>Acrania/anencephaly</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Skeletal dysplasia</td>
<td>2</td>
<td>1 with central nervous system comorbidity</td>
</tr>
<tr>
<td>Cardiac defect</td>
<td>1</td>
<td>Numerous nonspecific lesions</td>
</tr>
<tr>
<td>Nonimmune hydrops</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Trisomy 18</td>
<td>1</td>
<td>Cardiac lesion</td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>1</td>
<td>Severe hydrops in 2nd trimester</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Outcomes</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Termination</td>
<td>6</td>
<td>2 stillborn, 3 neonatal deaths, 1 discharged home</td>
</tr>
<tr>
<td>Routine care</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Hospice care</td>
<td>3</td>
<td>1 stillborn, 1 neonatal death, 1 discharged home</td>
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Thirty-nine interviews were conducted: 9 conjoint; 25 individual interviews with women; and 5 individual interviews with men. There were 11 interviews with women near or around the original due date; 3 interviews 4 months after the due date, and 5 interviews one year after the diagnosis. Four men had second interviews (3 conjoint and 1 individual). Six men asked to be interviewed with their partners. One man, initially interviewed alone, asked to be interviewed with his wife after their infant’s death.

Diagnosis: “Enough confirmation”

Participants, especially the women, described in great detail the events of the ultrasound examination in which the fetal defect was either first suspected or confirmed. Four of the 10 men were present at this examination, and although they described their shock and anguish at the findings, each expressed deep sorrow for and protectiveness toward their wives/partners. Several women described a sense of foreboding before the examination. One primigravida had a sense that the pregnancy was not progressing normally, and at the time of the diagnosis of bilateral renal agenesis, she was “shocked but not surprised.” A mother of a 3-year-old child had vague pregnancy discomforts not experienced previously, and attributed the strange symptoms to a fetal defect, even prior to prenatal testing. Although her husband did not take the concern seriously, she was “not surprised” when the triple screen was suspicious for a genetic defect. Although she learned definitively via amniocentesis that the fetus had Trisomy 18, she described the “strawberry-shaped skull” that she saw during the ultrasound examination as “enough confirmation” that the fetus was thus impaired: “the amnio just told me what I already knew.”

The women were highly attuned to minute changes in the behaviors of the person performing the ultrasoundography. Even a slight turning away of the screen from the woman’s view, prolonged examination, change in facial expressions and increasing silence all forewarned the women of a problem. Women experienced a great deal of anxiety during these examinations that were not following the trajectory they expected; even women in the first pregnancy sensed when the examination was taking too long or that the emotional tenor in the room had changed subtly. One of the four men noticed these changes. Noncommunication by the ultrasonographer was highly distressing, especially when they left the room to consult with a physician without any explanation. Although one woman described it as “nerve-wracking,” she understood that “it was not her job to tell us what was wrong.” Another woman listened to the quiet discussions of 2 perinatologists summoned to look at abnormal findings. On hearing the word hydrops she “got [her fiancé] to hand me my Blackberry, and I Googled it right there while I was laying there just waiting. And I told him, ‘this is not good.’” Despite their distress and anxiety, the extent to which one woman vomited, fewer than half of the participants reported that providers paid attention to their emotional state while the determination that the fetus had a defect was in progress.

Prognosis: “Fact from fiction”

Once the diagnosis had been made, women and their partners typically saw several specialists, especially if the diagnosis was severe but not clearly lethal. One woman explained that after seeing numerous physicians, “They said they pretty much do not know what would have to actually be done ‘til the baby’s born because they don’t know. Um, he just kind of gave us different situations, best, worst.” Some couples noted what appeared to them to be competing interests of various specialists. One woman sensed that her best interests were not attended to, suspecting that those of other professionals took priority: “They [the providers] weren’t the experts, they didn’t want to tell too much, because that was not their area of expertise, and they didn’t want to step on anybody’s toes and get themselves in trouble. blah blah blah, but yeah, we went out with pretty much half-assed information.”

Most couples sought information from the Internet as a means of understanding the fetal condition. Searching
at home meant that they could regulate the amount and type of information that they were getting, although most recognized that they had to, as one woman cautioned, “be careful to separate fact from fiction.” Another woman who searched the Internet for “how and why this [anencephaly] happened” described her responses to others who asked what was wrong: “We’re like, we don’t know. That’s exactly how we felt. We just don’t know.” Although they knew many facts about anencephaly generally, this couple’s truth was that not understanding the reasons for the defect was very problematic; facts per se about the defect were insufficient to respond adequately to inquiries about what was wrong.

What to do: Creating truth in the aftermath of a severe fetal diagnosis

Although the initial diagnostic and prognostic processes were similar across all participants, the construction of truth and to whom and how they told their story varied, depending on how and when the pregnancy ended.

Termination: “Really sort of the truth”

Six of the women terminated the pregnancy after the diagnosis of an unequivocally lethal defect: anencephaly, Trisomy 21 with extensive fetal hydrops, Trisomy 18 with cardiac anomalies, bilateral renal agenesis (2), and severe nonimmune hydrops. Three women who had not given birth previously underwent dilatation and evacuation (D&E) under general anesthesia. The 3 who elected to terminate via labor induction had given birth at term previously.

Constructions of truth began early for women who terminated. No single description typifies their experiences, except that the use of the word termination was not part of their everyday language in describing how the pregnancy ended. The D&E was “the surgery” or “the procedure.” Termination by labor induction was simply “induction” or “labor.” One woman described the decision to have labor induced: “I was given the option as to whether I wanted to induce or whether I wanted to actually do the other termination, and I felt like that it would be best for me to induce labor. I felt like I came that far and I couldn’t imagine terminating at that point.” Despite recognizing that by having labor induced she was in fact ending the pregnancy, a D&E guaranteed that “there’s not a chance that a baby’s gonna come out intact,” the prospect of which weighted the decision in favor of induction. Their partners deferred to the woman’s preference for how to terminate, as the procedure involved their bodies, not the partner’s.

Women with lethal fetal diagnoses had interactions with providers, especially physicians, which underscored for them the poignant and troublesome nature of their situation. Well-meaning manipulation of facts by a physician served to “briefly reassure” one woman for 2 days that she “[didn’t] need to worry about Down syndrome” when in fact the alpha-fetoprotein (AFP) level was so high as to be “almost diagnostic of a neural tube defect.” She interpreted his actions as being “really nice and nurturing” despite understanding later “with a positive on the AFP that it means that there’s something wrong.” One woman’s encounter with a consulting physician who confirmed that the fetus was lethally impaired left her feeling “brushed off, maybe it wasn’t as important” as she was “told with no compassion” that the fetus had no kidneys or bladder. Furthermore, the doctor’s unsolicited advice at the moment was, “What do you want to do? My suggestion is for you to terminate.” Despite ultimately terminating, she found having the issue pressed so soon after diagnosis to be very upsetting, and ultimately sought care elsewhere.

One woman suffered alone through an egregious episode in an affordable local abortion clinic near the military base where her husband was stationed after learning that their health insurance would not cover pregnancy termination despite the lethal fetal defect. “Crying uncontrollably” as she was being prepared to end the wanted pregnancy, she told the physician that she wanted “to know everything that is going on” during the D&E. Her emotional request was met with a cruel moment-by-moment litany by the provider who explained, “That’s your baby’s head cracking,” a sound that she had since heard “over and over” in her mind. The facts of the D&E that she thought she wanted to know were untempered by professional restraint.

Women who terminated faced explaining to various constituencies what had happened to the pregnancy. All of them told adult members of their immediate families about the fetal defect and were supported in their decision to terminate. Each woman explained to less intimate others, such as work associates or casual friends, that she had experienced “a miscarriage,” which, as one woman described was, “...really sort of the truth. It was a fact that the baby wasn’t going to live.” One woman who had confided “the truth” to a colleague who failed to “keep [my] secret” was surprised that she was supported by coworkers when “the truth got out” about the fetal defect and subsequent labor induction. Only one woman used the word abortion in describing the termination. She explained that she only used this word during interviews, using the word “miscarriage” otherwise in social discourse. Partners told only colleagues and friends on a need-to-know basis, such as superior officers and employers, often using the phrase “lost the baby” as an easily understood and uncomplicated explanation of the pregnancy outcome.
Routine care: “It’s not the worst thing we’ve seen”

Of the 9 women who continued the pregnancy, 6 wanted routine prenatal care and obstetrical intervention and neonatal intervention. Only 1 infant survived. Fetal defects in this group, although diagnosed with a high degree of certainty, had prognoses that were less definitive than were the defects among the women who terminated. An exception was one woman who, despite fetal anencephaly, requested routine care with full intervention.

These situations, with the one exception, were fraught with ambiguity over the eventual outcome. Prognosticating the murky futures was often cast in terms of “odds” that varied widely over the pregnancy. Women and men both clung to these odds as important indicators of the chances of fetal or neonatal survival. One young wife and husband independently cited the improving odds of survival given by their obstetrician based on continuing fetal growth. She expressed their increasing hope for a good outcome based on these calculations, “Basically we’ve told our family and we tell each other every day, he’s going to be fine. You know, at first they started us out with a 50/50 chance that he was going to survive. Now he has an 80% chance he’s going to survive. He [the obstetrician] said judging by, you know, your diaphragmatic hernia, it’s not the worst thing we’ve seen and you have a lot of good factors… you know, our child has so much of a better chance.” The husband echoed her optimism. The baby died within minutes of birth at term after vigorous resuscitation, causing the wife to reflect ruefully, “I just remember that, her [the pediatrician] saying that it wasn’t supposed to happen like that… it wasn’t supposed to happen. But like the nurse and the doctors and stuff were just like totally stunned that you know, it, it was like that.” What had begun as a long shot for survival causing the couple to consider termination at 14 weeks ended as a crushing disappointment tainted with anger over the unexpected neonatal death.

Odds were “irrelevant” to the young woman whose anencephalic fetus was given “zero chance” of survival by every provider she encountered. Believing that any thoughts that the baby would die indicated a lack of religious faith on her part, she had to be told that the lifeless infant was indeed dead even as she held him in her arms at birth. After she and her husband had “a sad moment,” she quickly found comfort in her faith, underestimating the baby’s fate as “in God’s hands.” Their desire for full intervention during pregnancy and delivery constituted an ethical dilemma for the providers whose different framework and understanding of the fetal condition left them reluctant to monitor the fetus in labor and unwilling to intervene for signs of distress. Rather than creating a tense situation, the obstetric team simply did not monitor the fetus during labor. The young woman, who had no previous obstetric experience on which to draw, expressed gratitude at how kind everyone had been, never questioning the labor management although the fetus died between her admission to the labor and delivery unit and delivery several hours later.

Perinatal end-of-life care: “Knowing what we knew was going to happen…”

Three women who continued the pregnancy were provided perinatal end-of-life (EOL) care. Two of the fetuses had unequivocally lethal conditions, and the third was diagnosed with nonspecific cardiac defects thought to be inoperable. For 2 of these women, the fetal diagnosis had little impact and was secondary to complex contemporaneous social issues unrelated to pregnancy. One couple had a very clear understanding of the lethality of fetal anencephaly; however, their religious faith proscribed termination. They shared the diagnosis and prognosis with family and friends openly, finding this comforting. Fetal movement helped the wife replace her sadness: “The day when I felt that baby start to move, I start to feel more affection for him and then the sadness started going away.” The husband echoed these sentiments: “Knowing what we knew about what was going to happen; I think we tried to have a little bit more of love for him.” Their son lived 8 hours, held his entire life by his parents, family members, and friends. His birth and death were honored in a well-attended church service where the husband served as a part-time pastor. This couple felt supported throughout the pregnancy and subsequent neonatal death by both the healthcare community and their extended family and numerous friends. For this couple, the facts and their truth were closely aligned.

DISCUSSION

Questions of virtue as person-centered right action and truth telling were a dimension of having a severe fetal diagnosis. Participants’ stories reflected their pain on learning of the fetal defect and the impact of the providers’ words and demeanor in relaying the news that the fetus was likely to die. In turn, couples faced telling family and others in their social network about the troubled pregnancy and likely outcomes. Women who terminated had to decide between a D&E and labor induction, and then calculate what and with whom to share their experience. Those who had routine perinatal care faced an uncertain outcome through the rest of the pregnancy; these uncertainties were often cast
by well-meaning providers as “odds” of survival upon which couples placed great emphasis.

Providers’ interactions with couples were usually, but not always, characterized by the practice of phrenosis, a “virtuous quality enabling one to judge the right means to the good end.” When phrenosis was paired with theoretical wisdom (knowledge), providers were positioned to assist women and their partners in deliberating the various options available to them in the aftermath of the diagnosis. The tragic implications of the severe fetal diagnosis were moderated when providers did not simply relay the facts as determined by prenatal testing, but demonstrated those qualities of professional virtues of competence, deliberation, diligence, genuineness, and courtesy. Relaying information untempered by these professional virtues resulted in a high degree of distress to these couples, who suffered the dual insult of learning of the fetal diagnosis through uncaring, morally bereft interaction. Fractious interactions were prominent in participants’ narratives, suggesting that the moral weight of negative encounters with providers may be more significant than that of positive encounters.

Couples were in a more complex moral situation than were providers. Providers’ relationships with patients are clearly defined by professional ethical standards, providing them with a delimited context within which to interact. The women and men, on the contrary, ventured from this delimited context into a much wider social network of family, friends, and colleagues. Deciding what to do was the first order of business once the diagnosis and prognosis were as clear as they could be; who and what to tell quickly followed.

For women who terminated, “truth telling” became an exercise in finding a means of relaying their loss without disclosing the specific mechanism by which the loss occurred. Sandelowski and Jones referred to these narrative devices as “healing fictions,” especially with regard to constructions of choice. These are not falsehoods, but are “strategic arrangements of ‘objective’ events…intended to impose order [and] create meaning…” For the couples in this study, euphemistic language such as “miscarriage,” “lost the baby,” “surgery,” and “induction of labor” served to create a truth from the facts (“objective events”) that allowed them to terminate the pregnancy while preserving their privacy and protecting themselves from public scrutiny and negative judgment. Their creation of truth reflects moral agency, their phrenetic capacity to discern wise action in a tragic dilemma, making meaning through narratives that blunted the harsh edges of a prevailing negative social discourse related to abortion.

Couples who continued pregnancy faced a different set of issues related to truth telling. First, when the fetus was not definitely lethally impaired, couples continued the pregnancy under the specter of “odds” related to survival that were overly optimistic. The only clear truth was the pregnancy was continuing with some degree of fetal impairment. Hope trumped odds and most couples proceeded with usual activities associated with pregnancy, such as buying baby items. The eventual deaths of 5 of the 6 of the fetuses/neonates in this group left couples grappling for answers about what had happened.

Only one couple in the perinatal end-of-life care group had an experience that exemplified the goals of supportive anticipatory care and bereavement support during pregnancy and after the neonatal death of their anencephalic son. For the couple who continued pregnancy with perinatal end-of-life care, the outcome was “good” in the sense that existential wellness was created in contrast of a virtue-based helping relationship between providers and the couple. The fact that the fetus had an unequivocally lethal impairment relieved the couple of the problems related to a more ambiguous prognosis, such as those who had routine care. The continuation of pregnancy relieved the couple of engaging in “strategic arrangement of events” to veil a termination in socially approved language. Free from the constraints of ambiguity or relieved of calculating the risk and benefits of disclosure of a termination, this couple experienced a good outcome even in the midst of a profoundly sad event in their lives.

**Implications for nursing**

The holistic focus of nursing practice on therapeutic relationships and context of lives aligns closely with the underlying tenets of virtue ethics. Hodkinson examined the issue of how a nurse should approach truth telling from a virtue ethics perspective, arguing that the virtuous nurse, as a function of phrenosis, must weigh the various virtues at work in highly complex situations. In other words, the degree to which a nurse balances honesty (a virtue) and, for instance, compassion (a virtue) is contextually bound and warrants close examination as to the consequences of acting solely within the demands of one virtue and ignoring the other. For instance, the phrenetic nurse may elect to tell a patient upsetting news as a function of valuing veracity. But the nurse can also mediate the distressful truth by being compassionate: being fully present to the patient in the aftermath of the news, responding to questions, allowing the patient time and space to grieve or be angry, or talking with family members. In the case of severe prenatal diagnosis, the nurse may be of great assistance in helping couples work through very complex issues in preparation for decision-making and the aftermath of learning that their expected baby is likely to die. Although this
article has focused on virtue ethics in context of severe fetal diagnosis, the usefulness of a person-centered moral perspective extends to nursing encounters in every setting.

Few situations exist in healthcare as paradoxical as severe prenatal diagnosis; the moral weight of this complex circumstance is significant. Although the incidence of severe fetal defects is relatively uncommon, the increasing use of prenatal diagnostic technologies has increased the likelihood that perinatal nurses will provide care for couples who have advance knowledge that the pregnancy will end without a live infant. Examining the moral discourse that surrounds this paradoxical situation prepares nurses to provide nonjudgmental, supportive care to patients who face ethical dilemmas when birth and death are intertwined.

References