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Fetal Patients and Ethics Specialists: Advocating for a Humble Approach

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Abstract

In prenatal medicine, ethics consultation offers a way to distribute responsibility for complex choices, especially when moral intuitions alone fail to provide clear guidance. However, it remains uncertain whether the established principles of ethics consultation can be directly applied to the unique circumstances of pregnancy. Our analysis focused on the particular forms of disagreement, conflict, and uncertainty of values that arise in prenatal care, and how an ethics consultation service (ECS) might address them, supported by a case illustration. At present, ethics facilitation and conflict resolution lack a universally accepted normative framework that covers prenatal diagnosis, therapeutic interventions, and reproductive decision-making. Nevertheless, these approaches can still support ethically demanding situations in prenatal medicine if two conditions are observed: (a) ECSs should avoid issuing prescriptive, content-heavy recommendations, and (b) they should not initiate conflict mediation that places the pregnant woman or couple as one of the disputing parties. It is essential for both ethics consultants and healthcare practitioners to recognize the current constraints and risks of ethics consultation in prenatal medicine, while collaboratively contributing to the development of standards tailored to this highly complex field.

Keywords: Professional ethics, Prenatal medicine, Ethics consultation

Background

Ethics consultation in pregnancy

Prenatal and maternal–fetal medicine presents a range of unique ethical dilemmas. These challenges emerge not only in situations involving the potential termination of pregnancy but also due to the expanding spectrum of prenatal diagnostic and therapeutic options. Consequently, prenatal medicine has become a frequent arena for ethics consultation services (ECSs). Although systematic data are lacking, limited single-center reports suggest that pregnancy-related issues—particularly those concerning termination—commonly lead to ethics referrals [1–4]. In some institutions, ECS involvement is mandatory in decisions regarding late-term termination [5], and in others, specialized ECSs have been created to address prenatal testing and selective terminations [6,7]. Within this setting, ethics consultation is often regarded as a way to distribute responsibility in navigating difficult choices, especially when moral intuitions fail to provide clarity. Still, several questions remain: Is pregnancy merely one additional area for ethics consultation alongside end-of-life care or psychiatry? Can established ethics consultation standards be applied directly to this highly specific setting? And what should clinicians realistically expect from ECSs in prenatal medicine?

To explore these questions, we use a case example to highlight the distinctive ethical complexities of prenatal medicine and to show how a facilitation-based ECS approach might respond.

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Case example

A neonatologist, consulted by fetal medicine specialists, referred a case to the ECS involving a pregnant woman whose fetus showed multiple malformations on ultrasound, most likely linked to a chromosomal disorder such as an autosomal trisomy. The anomalies were profound and considered incompatible with survival beyond a few hours or days.

The neonatologist requested an amniocentesis at 24 weeks' gestation, anticipating that cytogenetic confirmation would justify withholding resuscitation at birth and providing only supportive care. Meanwhile, the parents expressed their wish for the baby to be delivered naturally and cared for without aggressive resuscitation. However, the clinical team informed the mother that intensive resuscitation would be unavoidable at delivery unless she consented to amniocentesis. The referral to the ECS was intended to help resolve the conflict between the medical team and the couple, with some hope that ECS involvement might "persuade" the parents toward the procedure, even though the test might not have yielded a definitive chromosomal result. The underlying concern from the neonatologist was that, absent such confirmation, some clinicians might insist on pursuing futile full resuscitation.

The method of ethics consultation

ECSs are generally carried out by committees, teams, or individual consultants who intervene upon request [8,9]. Requests are usually made by healthcare providers, patients, or families who encounter ethical conflict or uncertainty in decision-making related to values or norms.

In the presented case, the dispute between the clinical team and the couple centered on the ethical justification for an invasive diagnostic procedure—amniocentesis—given the clinical context. The disagreement ultimately prompted involvement of the ECS.

In such cases, an ethics consultation service (ECS) is expected to "enhance the quality of health care by identifying, analyzing, and resolving ethical concerns or questions" [8]. Yet, significant disagreements persist—not only regarding the proper methods but also concerning the goals that ethics consultation should pursue [10] and the qualifications of those who should provide it [11]. The field of ethics consultation remains marked by a pronounced divide [12] between two primary models: the clinical consultation model and the facilitation/mediation model. The earliest ethics consultants, working some four decades ago, tended to deliver judgments, provide advice, or suggest specific courses of action [13]. In that role, they operated much like "clinical professionals with specialized expertise" who, on this basis, advised on the ethically preferable decision or conflict resolution [14].

By contrast, the more contemporary ethics facilitation model—endorsed by the American Society for Bioethics and Humanities as the "appropriate approach to ethics consultation" [8]—focuses on guiding stakeholders toward a "principled ethical resolution" [15] when value-based conflicts or uncertainties emerge in health care. Here, the ECS primarily uses skills in mediation and support, enabling health professionals, patients, and families to engage in sound decision-making. Although offering recommendations remains possible [8, 15, 16], this is no longer seen as the ECS's central function. For our discussion of ethics consultation in prenatal medicine, we place emphasis on the facilitation model, while noting that our analysis also bears relevance for applying the clinical consultation model in this setting.

Within the facilitation approach, the ECS assists the involved parties in three main ways [8, 15]: (a) clarifying the ethical dimensions of uncertainty or conflict, including both stated and underlying interests of all sides [15]; (b) identifying a spectrum of ethically acceptable options; and (c) supporting resolution of the conflict.

Understanding: Distinctive features of value conflicts in prenatal medicine

Prenatal medicine presents particularly complex conditions for ethics consultation. First, pregnancy is not inherently a medical illness, which means the standard physician–patient interaction models often fail to apply, since the aims of clinical practice in this context differ. Second, there is no single, clearly defined patient: medical actions generally affect both the pregnant woman and the embryo or fetus simultaneously. Some prenatal interventions are directed at preventing or detecting health problems in the woman, potentially making her a patient in her own right. More often, however, the focus of prenatal and perinatal medicine lies on the health of the fetus. Certain fetal interventions may even introduce risks for the mother while aiming to benefit the fetus. Third, the objective of prenatal medicine is not restricted to "health." In many cases, the

goal is to facilitate reproductive choice, which can shape the lives not only of the pregnant woman but also of the embryo or fetus.

In the case presented, attention was directed primarily toward the well-being of the fetus—or, more precisely, the prospective child—which became the central concern. The health of the pregnant woman herself was not foregrounded in the deliberations, though it was indirectly influenced by the decision. The neonatologist, as the physician responsible for the child's future health, emphasized the presumed interests of the fetus by seeking diagnostic confirmation of the severe prognosis before agreeing to palliative measures. Beyond this, the medical team also had its own institutional interest: to protect the integrity of clinical decision-making, particularly in life-limiting contexts, and to reduce potential legal risks. By contrast, the woman's possible interests—such as avoiding an invasive procedure, or perhaps choosing not to raise a child with severe malformations, as well as her desire to minimize her child's suffering through palliative care regardless of genetic test outcomes—were treated as secondary. From the standpoint of ethical principles, the debate among professionals was largely framed in terms of beneficence and non-maleficence toward the fetus and the future child, while the pregnant woman's reproductive autonomy and her own well-being were afforded comparatively little weight.

Overall, prenatal medicine presents a set of ethical challenges distinct from those that arise in areas such as end-of-life care. The uniqueness stems from the nature of pregnancy, where the pregnant woman and fetus are intimately connected physically and emotionally, yet their interests and rights can sometimes appear to be in conflict. In this context, the ECS, as an independent and impartial party, can play a valuable role in disentangling the different explicit and implicit interests and in clarifying their ethical significance. Still, the question remains: what further contributions can an ECS provide in prenatal medicine? And how might such complex disputes be resolved?

Defining: What constitutes a principled resolution?

A central role of ethics facilitation is to establish the boundaries of what counts as an ethically acceptable—or "principled"—solution. These boundaries are typically shaped by widely recognized ethical principles, legal requirements, and moral norms articulated in ethical discourse, legislation, and court rulings [15]. Yet in prenatal medicine, the absence of a universally agreed-upon framework makes this task exceptionally difficult [17]. The field continues to be marked by deep and contentious debates over core questions such as the moral status of unborn life [18], as well as broader issues of justice [19,20] and discrimination [21] related to prenatal testing.

To sidestep the deep philosophical disputes surrounding the moral status of the fetus, some scholars have attempted to establish a normative foundation for prenatal medicine that does not rely on such claims. Beginning in the 1980s, McCullough and Chervenak outlined professional responsibilities in this field [22]. They proposed that a fetus could be regarded as a patient when presented as such by the pregnant woman, thereby granting it a dependent moral status tied to beneficence-based rather than rights-based duties of health care professionals. Yet, this framework remains controversial and heavily debated [23–25]. The authors emphasized that the designation of a fetal patient does not necessarily separate the fetus from the pregnant woman, nor does it commit one to recognizing an independent moral status [26]. Still, many interpret the term "patient" as implying precisely that—individual separateness and independent moral status [24]. This unresolved tension lies at the heart of their proposal.

The so-called "pragmatic concept" [26] of a dependent moral status, which gains weight as gestation advances, resonates with many health professionals and the public. The difficulty, however, is grounding such a status in the social role of "patient." As Lyerly and colleagues observed, the prototypical patient is understood in medicine as a distinct, individuated entity, one that can be examined, diagnosed, and treated in isolation [24]. Critics argue that applying this framework to the fetus risks distorting both the moral status of the fetus and the rights of pregnant women, by portraying the woman as a mere "environment" for the fetal patient rather than a person in her own right [27–29]. A more promising route may lie in situating the fetus's dependent moral status within a different framework—such as the rights or interests of the future child—without conferring on it the role of "patient." However, no broadly accepted normative model for physician–patient relationships in prenatal medicine has yet been established [28, 30].

In practice, this leaves ECSs without universally recognized standards for addressing conflicts between the interests of the pregnant woman and those of the

future child. According to McCullough and Chervenak, key determinants include gestational age (viability) and the availability of interventions that clearly benefit the fetus [22]. Even then, beneficence-based duties to the fetus must be carefully balanced against obligations grounded in the autonomy and well-being of the pregnant woman. On their account, pressuring or compelling a woman to undergo amniocentesis could not be justified ethically.

Alternative perspectives on professional ethics in prenatal medicine—particularly those that give priority to the pregnant woman and view fetal interests as inseparable from maternal interests [28]—may reject altogether the notion of a distinct beneficence-based obligation to the fetus. Such approaches would likely narrow the range of ethically defensible solutions. Another unresolved question concerns the informational rights (or interests) of the future child. Expansive prenatal genomic testing could undermine a future person's right not to know their own genetic information, creating potential conflicts with parental or maternal choices [17].

Taken together, these considerations suggest that ECSs should be transparent about the existing plurality and indeterminacy of ethical frameworks in prenatal medicine. Their role is to work collaboratively with clinicians to deliberate over competing approaches and assess their relevance for each consultation request. In the absence of a widely accepted normative consensus, issuing content-heavy recommendations is problematic, since such guidance could appear arbitrary and be difficult to defend. For this reason, ECSs should refrain from doing so.

Defining: The unique challenge of reproductive choice

In situations where prenatal medicine is directed not toward prevention or treatment—as in the case example—but toward reproductive choice, the ethical complexity increases. Tests such as those for fetal aneuploidies are primarily intended to support informed reproductive decisions, even though they cannot prevent chromosomal abnormalities or provide treatment. These decisions closely parallel predictive testing for hereditary genetic disorders, where the person at risk is the central decision-maker and beneficence-based reasoning has only limited relevance. In the same way, prenatal decisions often revolve around the private deliberations of the pregnant woman or couple—essentially, "Given that we want a child, do we want to have this particular child?"—with physicians supplying medical information but carrying only minimal responsibility beyond that. A second layer of decision-making belongs to the health care professionals, who must grapple with their own ethical obligations, such as whether it is appropriate to offer specific prenatal tests when the outcomes may serve primarily to inform parental choices and potentially result in pregnancy termination.

Ethics consultations can strongly influence both these processes. Evidence from case series illustrates this impact: in Switzerland, ethics consultations in obstetrics declined to support the pregnant woman's or couple's wishes in 9 of 15 termination-related cases [4]; similarly, in Germany, 4 of 13 requests for late termination were judged ethically unacceptable [5]. The basis on which these determinations were made is rarely transparent. Unlike other clinical contexts, these cases involve not only two possible patients but also differing aims—supporting reproductive choice on the one hand and potentially ending a pregnancy on the other. If the principal goal of clinical action in such contexts is to foster reproductive autonomy, how can it be ethically justified for an ECS to override the pregnant woman's autonomy so decisively? Moreover, is it suitable for ECSs to issue case-by-case recommendations in such morally charged situations, or would it be more appropriate to establish broader, principled guidelines?

These unresolved issues highlight the need for a stronger theoretical foundation for ethics consultation in matters of reproductive choice. Until such a framework is established, the role of ECSs in these cases will remain constrained and their scope of contribution limited.

Resolving: Conflict mediation in prenatal medicine

When disagreements arise, an ethics consultation service (ECS) typically seeks to bring all stakeholders into a structured dialogue in which every perspective is acknowledged and safeguarded [15], with the goal of reaching a shared resolution. In prenatal contexts, the perspective of the pregnant woman or couple is central and must eventually be heard. The more difficult issue is how to represent the fetus, and particularly the prospective child, within such a process—even when one interprets fetal interests as inseparably linked to maternal interests.

Without invoking debates about fetal or embryonic rights, there are still many situations in which the unborn

child appears to be the intended recipient of medical interventions (such as prenatal therapy), or where the child's future welfare is directly implicated. This may occur when diagnostic procedures reveal information that could disadvantage the child later in life, or when attempted treatments introduce risks of harm or impairment. With expanding diagnostic technologies (e.g., non-invasive prenatal testing or fetal genome sequencing) and emerging therapeutic possibilities that could profoundly shape a child's future, any mediation process that fails to consider the future child's perspective seems incomplete.

ECSs might note that parallel situations exist elsewhere in medicine, where the patient is incapable of voicing preferences due to severe illness. In those cases, clinicians and family members work together to interpret and represent the patient's likely wishes, ensuring they are "more than a phantom at the table" [15]. Established mechanisms such as surrogate decision-makers or advance directives facilitate this representation. The challenge in prenatal medicine is unique: the fetus has not yet developed preferences or values, and the pregnant woman—who is simultaneously a potential patient—has an intimate physical and emotional bond with the fetus. While she and her partner will hold custody of the child after birth, this role cannot simply be assumed in advance during pregnancy, as any medical decision directly affects her own body and well-being. Bringing in an external figure—whether a clinician, ethicist, social worker, or legal authority—as a stand-in for the fetus or future child would likely be perceived as an unacceptable intrusion into this intimate maternal-fetal relationship.

In the case under discussion, it initially appears reasonable for the pregnant woman and her partner to act as representatives for the fetus and future child in mediation. The welfare of the fetus and the child-to-be is the principal concern, while the amniocentesis procedure itself carries minimal risk for the woman. At this stage, the possibility of a significant "internal" conflict of interest for her seems limited. However, a preliminary consultation with the couple might uncover deep anxieties about raising a severely disabled infant with a short life expectancy. Such concerns could reshape the conflict, prompting the couple to favor palliative care rather than more aggressive interventions.

Although the pregnant woman or couple naturally represent the interests of the fetus or future child during mediation, there are situations in which assuming this role may place an excessive burden on them—for example, when they are experiencing an internal "pregnancy conflict." In such cases, a mediation session involving both the couple and the professional team may be ineffective and could impose considerable stress on the woman and her partner, making it ethically problematic. Instead, a series of smaller, private meetings with the pregnant woman or couple can help clarify internal conflicts and lay the groundwork for ethically sound conflict resolution.

Conclusion

In cases involving prenatal diagnosis and therapy, the primary responsibility of an ECS is to recognize its own limitations while actively contributing to the refinement and theoretical grounding of ethics consultation in this field. Pregnancy represents a unique context, distinct from other areas in which ECSs typically operate. Applying general ethics consultation standards without careful adaptation carries significant risks for all parties—the pregnant woman or couple, the fetus or future child, and the health care professionals involved.

An ECS adopting a facilitation approach should transparently communicate the variability and ambiguity of ethical concepts in prenatal medicine and refrain from issuing content-heavy recommendations, particularly in matters of reproductive choice. When there are indications of a pregnancy-related internal conflict, preliminary meetings with the pregnant woman or couple are crucial before considering a larger joint mediation session.

Clinicians play a central role in shaping appropriate standards for ethics consultation in prenatal medicine. Their practical experience with day-to-day ethical challenges is essential for navigating between professional ethical principles and moral intuitions, helping to construct a robust normative framework for this specialized field. For instance, when the moral intuition of fetal patienthood conflicts with established principles of moral status and the reproductive rights of the pregnant woman, interdisciplinary collaboration may allow for the development of a more ethically coherent alternative. Until a comprehensive normative framework is established, ECSs should proceed with caution, adopting a modest and reflective approach that emphasizes understanding, provides a space for dialogue, and engages in Socratic questioning. Such a practice is not only constructive and useful but fundamentally ethical.

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