Refusal of Medically Recommended Treatment During Pregnancy

ABSTRACT: One of the most challenging scenarios in obstetric care occurs when a pregnant patient refuses recommended medical treatment that aims to support her well-being, her fetus's well-being, or both. In such circumstances, the obstetrician–gynecologist’s ethical obligation to safeguard the pregnant woman’s autonomy may conflict with the ethical desire to optimize the health of the fetus. Forced compliance—the alternative to respecting a patient’s refusal of treatment—raises profoundly important issues about patient rights, respect for autonomy, violations of bodily integrity, power differentials, and gender equality. The purpose of this document is to provide obstetrician–gynecologists with an ethical approach to addressing a pregnant woman’s decision to refuse recommended medical treatment that recognizes the centrality of the pregnant woman’s decisional authority and the interconnection between the pregnant woman and the fetus.

When a pregnant woman refuses medically recommended treatment, her decision may not result in optimal fetal well-being, which creates an ethical dilemma for her obstetrician–gynecologist. In such circumstances, the obstetrician–gynecologist’s ethical obligation to safeguard the pregnant woman’s autonomy may conflict with the ethical desire to optimize the health of the fetus. The obstetrician–gynecologist’s professional obligation to respect a pregnant patient’s refusal of treatment may conflict with his or her personal values. Forced compliance—the alternative to respecting a patient’s refusal of treatment—raises profoundly important issues about patient rights, respect for autonomy, violations of bodily integrity, power differentials, and gender equality. Coercive interventions often are discriminatory and act as barriers to needed care.

The purpose of this document is to provide obstetrician–gynecologists with an ethical approach to addressing a pregnant woman’s decision to refuse recommended medical treatment that recognizes the centrality of the pregnant woman’s decisional authority and the interconnection between the pregnant woman and the fetus. This document is not intended to address professional liability or legal issues that may arise in association with decision making when a pregnant woman refuses medically recommended treatment. Information regarding professional and legal issues is available elsewhere (see www.acog.org/About-ACOG/ACOG-Departments/Professional-Liability and the American Congress of Obstetricians and Gynecologists’ Professional Liability and Risk Management: An Essential Guide for Obstetrician–Gynecologists, 3rd edition). Fellows are encouraged to seek legal advice when concerns arise regarding professional liability or the legal implications of their actions.

Recommendations

On the basis of the principles outlined in this Committee Opinion, the American College of Obstetricians and Gynecologists (the College) makes the following recommendations:

• Pregnancy is not an exception to the principle that a decisionally capable patient has the right to refuse
treatment, even treatment needed to maintain life. Therefore, a decisionally capable pregnant woman’s decision to refuse recommended medical or surgical interventions should be respected.

- The use of coercion is not only ethically impermissible but also medically inadvisable because of the realities of prognostic uncertainty and the limitations of medical knowledge. As such, it is never acceptable for obstetrician–gynecologists to attempt to influence patients toward a clinical decision using coercion. Obstetrician–gynecologists are discouraged in the strongest possible terms from the use of duress, manipulation, coercion, physical force, or threats, including threats to involve the courts or child protective services, to motivate women toward a specific clinical decision.

- Eliciting the patient’s reasoning, lived experience, and values is critically important when engaging with a pregnant woman who refuses an intervention that the obstetrician–gynecologist judges to be medically indicated for her well-being, her fetus’s well-being, or both. Medical expertise is best applied when the physician strives to understand the context within which the patient is making her decision.

- When working to reach a resolution with a patient who has refused medically recommended treatment, consideration should be given to the following factors: the reliability and validity of the evidence base, the severity of the prospective outcome, the degree of burden or risk placed on the patient, the extent to which the pregnant woman understands the potential gravity of the situation or the risk involved, and the degree of urgency that the case presents. Ultimately, however, the patient should be reassured that her wishes will be respected when treatment recommendations are refused.

- Obstetrician–gynecologists are encouraged to resolve differences by using a team approach that recognizes the patient in the context of her life and beliefs and to consider seeking advice from ethics consultants when the clinician or the patient feels that this would help in conflict resolution.

- The College opposes the use of coerced medical interventions for pregnant women, including the use of the courts to mandate medical interventions for unwilling patients. Principles of medical ethics support obstetrician–gynecologists’ refusal to participate in court-ordered interventions that violate their professional norms or their consciences. However, obstetrician–gynecologists should consider the potential legal or employment-related consequences of their refusal. Although in most cases such court orders give legal permission for but do not require obstetrician–gynecologists’ participation in forced medical interventions, obstetrician–gynecologists who find themselves in this situation should familiarize themselves with the specific circumstances of the case.

- It is not ethically defensible to evoke conscience as a justification to attempt to coerce a patient into accepting care that she does not desire.

- The College strongly discourages medical institutions from pursuing court-ordered interventions or taking action against obstetrician–gynecologists who refuse to perform them.

- Resources and counseling should be made available to patients who experience an adverse outcome after refusing recommended treatment. Resources also should be established to support debriefing and counseling for health care professionals when adverse outcomes occur after a pregnant patient’s refusal of treatment.

**Refusal of Treatment**

When a pregnant woman refuses recommended medical treatments or chooses not to follow medical recommendations, there can be a range of minor to major risks to the patient or the fetus. In certain situations, a pregnant woman might refuse therapies that the medical professional believes are necessary for her health or survival, that of her fetus, or both. Examples of these situations include a pregnant woman refusing to treat a fetal condition or infection in utero or to undergo cesarean delivery when it is thought to be medically necessary to avoid an adverse fetal or maternal outcome.

Such cases can be distressing for the health care team. Obstetrician–gynecologists may feel deep concern for the pregnant woman and fetus entrusted to their care, worry about the pregnant woman’s reaction if a potentially avoidable adverse outcome occurs, or be apprehensive regarding liability issues resulting from an adverse outcome. Members of the health care team may disagree about case management and feel uneasy about their roles or even experience moral distress (1).

In these circumstances, as in all clinical encounters, the obstetrician–gynecologist’s actions should be guided by the ethical principle that adult patients who are capable decision makers have the right to refuse recommended medical treatment. This doctrine has evolved through legal cases, regulations, and statutes that have established the requirement of informed consent to medical treatment in order to effect patient self-determination and preclude violations of bodily integrity. Informed refusal is the corollary of the doctrine of informed consent; it is an ongoing process of mutual communication between the patient and the physician and enables a patient to make an informed and voluntary decision about accepting or declining medical care. The informed consent process ideally begins before decision making so that the patient is able to make an informed choice (ie, informed consent or informed refusal) based on clinical information, the
Voluntariness is a background condition of informed consent. As noted in Committee Opinion No. 439, Informed Consent, “Consenting freely is incompatible with being coerced or unwillingly pressured by forces beyond oneself. It involves the ability to choose among options and select a course other than what may be recommended” (2). Pregnancy is not an exception to the principle that a decisionally capable patient has the right to refuse treatment, even treatment needed to maintain life. Therefore, a decisionally capable pregnant woman’s decision to refuse recommended medical or surgical interventions should be respected.

**Complexities of Refusal of Medically Recommended Treatment During Pregnancy**

In obstetrics, pregnant women typically make clinical decisions that are in the best interest of their fetuses. In most desired pregnancies, the interests of the pregnant woman and the fetus converge. However, a pregnant woman and her obstetrician–gynecologist may disagree about which clinical decisions and treatments are in her best interest and that of her fetus. As with a nonpregnant patient, a pregnant woman may evaluate the risks and benefits of recommended medical treatment differently than her obstetrician–gynecologist and, therefore, may refuse recommended therapies or treatments. Such refusals are based not only on clinical considerations but also on the patient’s roles and relationships; they reflect her assessment of multiple converging interests: her own, those of her developing fetus, and those of her family or community.

Special complexities are inherent in a woman’s decision to refuse recommended medical treatment during pregnancy because of the presence of the fetus. The maternal–fetal relationship is unique in medicine because of the physiologic dependence of the fetus on the pregnant woman. Moreover, therapeutic access to the fetus occurs through the body of the pregnant woman. A joint guidance document from the College and the American Academy of Pediatrics states that “any fetal intervention must be undertaken through the body of the pregnant woman who is the patient. Intervention on behalf of the fetus must be undertaken through the pregnant woman’s body. Thus, questions of how to care for the fetus cannot be viewed as a simple ratio of maternal and fetal risks but should account for the need to respect fundamental values, such as the pregnant woman’s autonomy and control over her body (15).

**Directive Counseling Versus Coercion**

When a physician is faced with a situation in which a patient refuses a medical recommendation, it is useful to distinguish the use of directive counseling from efforts aimed at coercion. Directive counseling is defined as patient counseling in which the obstetrician–gynecologist plays an active role in the patient’s decision making by offering advice, guidance, recommendations, or some combination thereof. Coercion is defined as the practice of compelling someone to do something by using force or threats. Directive counseling often is appropriate and typically is welcomed in the medical encounter because medical recommendations—when they are not coercive—do not violate but rather enhance the requirements of informed consent (2). However, if a patient refuses the recommended course of care, it is vitally
important that physicians recognize when they cross the line that separates directive counseling from coercion. Good intentions can lead to inappropriate behavior. The use of coercion is not only ethically impermissible but also medically inadvisable because of the realities of prognostic uncertainty and the limitations of medical knowledge. As such, it is never acceptable for obstetrician–gynecologists to attempt to influence patients toward a clinical decision using coercion. Obstetrician–gynecologists are discouraged in the strongest possible terms from the use of duress, manipulation, coercion, physical force, or threats, including threats to involve the courts or child protective services, to motivate women toward a specific clinical decision.

Although the physician aims to provide recommendations that are based on the best available medical evidence (16), data and technology are imperfect, and responses to treatment are not always predictable for a given patient. As such, it is difficult to determine the outcome of treatment—or lack of treatment—with absolute certainty. It requires a measure of humility for the obstetrician–gynecologist to acknowledge this to the patient and to herself or himself.

Because of the potential inability to determine with certainty when a situation will cause harm to the fetus, as well as the potential inability to guarantee that the pregnant woman will not be harmed by the medical intervention itself, a balance of potential outcomes that addresses the pregnant woman and her fetus should be presented. The obstetrician–gynecologist should affirm the importance of the pregnant woman’s assessment of her relational interests (personal, familial, social, or community) and acknowledge prognostic uncertainty. In addition, the following should be acknowledged: the limitations of the patient’s understanding of her clinical situation; cultural, social, and value differences; power differentials; and language barriers. When working to reach a resolution with a patient who has refused medically recommended treatment, consideration should be given to the following factors: the reliability and validity of the evidence base, the severity of the prospective outcome, the degree of burden or risk placed on the patient, the extent to which the pregnant woman understands the potential gravity of the situation or the risk involved, and the degree of urgency that the case presents. Ultimately, however, the patient should be reassured that her wishes will be respected when treatment recommendations are refused. When a pregnant patient refuses a recommended medical treatment, the physician should carefully document the refusal in the medical record. Examples of important information to document are as follows (17):

- The need for the treatment has been explained to the patient—including discussion of the risks and benefits of treatment, alternatives to treatment, and the risks and possible consequences of refusing the recommended treatment (including the possible risk to her health or life, the fetus’s health or life, or both)
- The patient’s refusal to consent to a medical treatment
- The reasons (if any) stated by the patient for such refusal

Arguments Against Court-Ordered Interventions

When the obstetrician–gynecologist and the patient are unable to agree on a plan of care and a pregnant woman continues to refuse recommended treatment, some obstetrician–gynecologists, hospital staff, or legal teams have attempted to force compliance through the courts, most notably for cesarean delivery or blood transfusion (18–20). Court-ordered interventions against decisionally capable pregnant women are extremely controversial. They exploit power differentials; involve incursions against individual rights and autonomy; and manifest as violations of bodily integrity and, often, gender and socioeconomic equality (14).

The College opposes the use of coerced medical interventions for pregnant women, including the use of the courts to mandate medical interventions for unwilling patients. Principles of medical ethics support obstetrician–gynecologists’ refusal to participate in court-ordered interventions that violate their professional norms or their consciences. However, obstetrician–gynecologists should consider the potential legal or employment-related consequences of their refusal. Although in most cases such court orders give legal permission for but do not require obstetrician–gynecologists’ participation in forced medical interventions, obstetrician–gynecologists who find themselves in this situation should familiarize themselves with the specific circumstances of the case. The College strongly discourages medical institutions from pursuing court-ordered interventions or taking action against obstetrician–gynecologists who refuse to perform them. It is not ethically defensible to evoke conscience as a justification to attempt to coerce a patient into accepting care that she does not desire.

Prognostic Uncertainty

Prognostic uncertainty is present to various degrees in all medical encounters across all specialties and is common enough in obstetric decision making to warrant serious concern about legal coercion and the tremendous effect on the lives and civil liberties of pregnant women that court-ordered intervention entails (15, 21). A study of court-ordered obstetric interventions suggested that in almost one third of cases in which court orders were sought, the medical judgment, in retrospect, was incorrect (22).

Barriers to Needed Care

Coercive and punitive policies are potentially counterproductive because they are likely to discourage prenatal care and successful treatment while undermining the patient–physician relationship. Attempts to criminalize
pregnant women’s behavior may discourage women from seeking prenatal care (23). Likewise, court-ordered interventions and other coercive measures may result in fear on the patient’s part about whether her wishes in the delivery room will be respected, which could discourage the pregnant patient from seeking care. Therefore, when obstetrician–gynecologists participate in forced treatment of their pregnant patients, outcomes for the patients and the fetuses may worsen rather than improve.

**Discriminatory Effects**

Coercive policies directed toward pregnant women may be disproportionately applied to disadvantaged populations. In cases of court-ordered cesarean deliveries, for instance, most court orders have been obtained against women of color or of low socioeconomic status. In a review of 21 court-ordered interventions, 81% involved women of color and 24% involved women who did not speak English as a first language (22). Likewise, a systematic review of more than 400 cases of coerced interventions found that most cases included allegations against low-income women (23). The inclusion of an ethics committee or a patient advocate could help mitigate the disproportionate application of coercive policies to certain subpopulations of women and should be made available whenever possible.

**Process for Addressing Refusal of Medically Recommended Treatment During Pregnancy**

Although there is no universal approach to communicating with and caring for a pregnant patient who refuses medically recommended treatment, steps can be taken to mediate conflict, diffuse intense emotions, and encourage consideration of the patient’s perspective. These steps may create space, even under time constraints, to ensure that patients are fully heard and considered.

**Seek to Understand the Patient’s Perspective**

Eliciting the patient’s reasoning, lived experience, and values is critically important when engaging with a pregnant woman who refuses an intervention that the obstetrician–gynecologist judges to be medically indicated for her well-being, her fetus’s well-being, or both. Medical expertise is best applied when the physician strives to understand the context within which the patient is making her decision. The obstetrician–gynecologist should acknowledge the importance of the pregnant woman’s knowledge and values when making medical recommendations. A pregnant woman’s decision to refuse treatment may be based on religious or cultural grounds; her assessment of the converging interests of herself, her fetus, her family, or her community; a misunderstanding of the clinical situation; or the experience of a family member or friend. Determining the basis for a pregnant woman’s decision to refuse medically recommended treatment enables the physician to address her concern or understand its importance to her and then take steps toward resolution (24). To that end, effective communication skills and strategies are critically important. Use of empathic statements, listening without interrupting, and taking a short break before revisiting the case can help defuse tensions, foster a calmer atmosphere, and establish trust (25, 26). The RESPECT model (Box 1) is an example of one tool that can be used to help optimize patient-centered care.

**Box 1. The RESPECT Communication Model**

<table>
<thead>
<tr>
<th>Rapport</th>
<th>Empathy</th>
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<tbody>
<tr>
<td>Connect on a social level.</td>
<td>Remember that the patient has come to you for help.</td>
</tr>
<tr>
<td>See the patient’s point of view. Consciously suspend judgment. Recognize and avoid making assumptions.</td>
<td>Seek out and understand the patient’s rationale for her behaviors or illness. Verbally acknowledge and legitimize the patient’s feelings.</td>
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<tr>
<th>Support</th>
<th>Partnership</th>
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<tr>
<td>Ask about and understand the barriers to care and adherence. Help the patient overcome barriers.</td>
<td>Be flexible with regard to control issues. Negotiate roles, when necessary.</td>
</tr>
<tr>
<td>Involve family members, if appropriate.</td>
<td>Stress that you are working together to address health problems.</td>
</tr>
<tr>
<td>Reassure the patient that you are and will be able to help.</td>
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<tr>
<th>Explanations</th>
<th>Cultural Competence</th>
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<tr>
<td>Check often for understanding. Use verbal clarification techniques.</td>
<td>Respect the patient’s cultural beliefs.</td>
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<th>Trust</th>
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<tbody>
<tr>
<td>Recognize that self-disclosure may be difficult for some patients.</td>
<td>Be aware of your own cultural biases and preconceptions.</td>
</tr>
<tr>
<td>Consciously work to establish trust.</td>
<td>Know your limitations in addressing medical issues across cultures.</td>
</tr>
</tbody>
</table>

Understand your personal style and recognize when it may not be working with a given patient.

communication. Physicians also are referred to additional College resources that relate to effective communication, cultural sensitivity, empathy, and health literacy (2, 26–30).

Enhance the Patient’s Understanding

Just as the patient must be free of external constraints on her freedom of choice, so must she be free of misinformation regarding the clinical factors on which the physician’s medical recommendations are formulated (2, 30). Adequate disclosure of relevant information may include that which is common to the practice of the profession, the reasonable needs and expectations of an ordinary patient, and, ideally, the needs and expectations of the patient making the decision. It also is important to inform the patient that other aspects of her care are not conditioned on making a choice that her obstetrician–gynecologist might prefer. Forthright and transparent communication of clinical information should encompass the range of clinical options available to the patient, including the potential risks, benefits, and consequences of each option and the likelihood of achieving goals of care. The discussion should include the treatment option that the patient prefers, as well as the benefits, risks, and consequences of no treatment or alternative treatments. Acknowledging that the patient is free at any time to refuse or withdraw her consent is an important part of the discussion. However, the physician should attempt to give the patient as much information as possible so that she has a basic understanding of her clinical situation and the implications of not receiving the treatment. Ideally, after the patient and the physician have discussed the clinical situation and the benefits and risks of the recommended treatment or intervention, the patient should decide whether or not to proceed with the recommended treatment (informed consent) or to forgo the recommended treatment (informed refusal).

Efforts to enhance patient understanding of relevant clinical information include the use of lay language rather than technical jargon, discourse in or translation to the patient’s primary language if the patient’s proficiency in English is limited, use of education materials such as those developed by the College, and efforts to mitigate patient stress (27, 30, 31). Most important is the acknowledgment that informed consent is an ongoing process, not an event or a signature on a document, and involves a willingness on the part of the obstetrician–gynecologist to engage in open, nonjudgmental, and continued dialogue.

Determine the Patient’s Decisional Capacity

A pregnant woman’s decision to refuse medically necessary treatment may occasion questions regarding her decisional capacity. Patients are, by law, presumed to be decisionally capable unless formally determined otherwise. The obstetrician–gynecologist should not infer from a patient’s decision to refuse treatment that the patient’s capacity to make medical decisions about proposed care is diminished. Disagreement with a physician’s recommendation is not, per se, evidence of decisional incapacity. Although psychiatric consultation may justifiably be sought when a pregnant woman’s decision-making capacity (ie, her capacity to understand her options and appreciate the potential consequences of her choice) is in question, in no circumstance should a psychiatric consultation be used as a punitive measure or viewed as a means to coerce a patient into making a specific decision. Genuine differences in how obstetrician–gynecologists and patients assess and balance risk; the pregnant woman’s assessment of the collective interests of herself, her fetus, her family, or her community; and religious beliefs and cultural meanings of interventions may all lead decisionally capable patients to choose options other than those strongly recommended by their obstetrician–gynecologists (25). When a patient has been determined to lack decisional capacity, the decisions of her legally authorized surrogate generally should be honored. Such decisions should reflect the patient’s previously expressed values and preferences when these are known.

Emergency Cases

Decision making can be particularly difficult and emotionally charged in emergency scenarios (32). Emergency cases may raise two distinct problems. First, fully informing the patient may not be possible. Nevertheless, a patient retains the right to make an uninformed refusal. Even if the patient has not been fully informed, a decisionally capable adult patient’s refusal of emergent care should be respected. Second, the patient may be incapacitated and, therefore, unable to consent for herself. “Presumptive consent” for critically needed care for a patient can sometimes be used, but only if it is critically necessary to proceed with care immediately (33) and a patient’s preference is not known. Use of presumptive consent is limited to emergency clinical situations in which the patient is completely decisionally incapable and no surrogate decision maker is reasonably available. Presumptive consent applies to cases in which an unconscious patient has not indicated a preference for treatment. Circumstances should support a reasonable presumption that the patient would retrospectively endorse the intervention. Expressions of disagreement or unwillingness preclude presumptive consent (33). A previously documented or expressed refusal should be respected.

Evaluate Maternal and Fetal Risk

Risk assessment during pregnancy poses unique challenges to patients and physicians. Interventions recommended during pregnancy and childbirth may reflect distortions of risk based on concerns about failure to intervene rather than robust considerations of risks associated with those interventions (34). Risk assessment in the context of a pregnant woman’s refusal of recommended treatment should address concerns regarding
the respective benefits of the procedure to the pregnant woman and the fetus, the probability of harm to the pregnant woman and the fetus from either performing or withholding the procedure, and the risks and benefits of less intrusive treatments, when available.

Interdisciplinary Team Approach
Obstetrician–gynecologists are encouraged to resolve differences by using a team approach that recognizes the patient in the context of her life and beliefs and to consider seeking advice from ethics consultants when the clinician or the patient feels that this would help in conflict resolution. The team may include colleagues from other disciplines, such as nursing, social work, chaplains, or ethics consultation. With the patient’s consent, it also may be helpful to include in the discussion members of the pregnant woman’s personal support network. However, these individuals cannot make the decision for the decisionally capable patient. Obstetrician–gynecologists are encouraged to consider seeking an ethics consultation and to discuss the clinical situation with their colleagues. A team approach can help increase the likelihood of realliance with the patient by underscoring that the patient’s concerns are shared among the health care team and her personal support system, particularly when the patient is included in the decision to use this collaborative approach.

Supporting the Patient and the Health Care Team When Adverse Outcomes Occur
When adverse outcomes occur after a pregnant patient’s decision to refuse recommended treatment, she may feel guilty about her decision, and members of the health care team may experience frustration and moral distress about whether they took all possible preventive measures. As with any adverse outcome, it is important that the patient and health care team members engage in honest communication and receive compassionate support.

Resources and counseling should be made available to patients who experience an adverse outcome after refusing recommended treatment. Patients can be reminded that medical decision making is complex and that well-intentioned people can make decisions they regret. The fact that the adverse outcome was not a certainty should be reinforced. Most critically, the clinical team’s efforts should be directed toward helping the woman with any grief that she may experience. Judgmental or punishing behaviors regarding the patient’s decision can be harmful.

Resources also should be established to support debriefing and counseling for health care professionals when adverse outcomes occur after a pregnant patient’s refusal of treatment. Medical practitioners can be reminded that respecting and supporting patients’ autonomy is a core ethical principle, even when it involves risk of adverse outcomes. Clinician grief and anger are understandable, but these feelings need to be processed outside of interactions with the patient. As with any adverse outcome, debriefing in a supportive context should be undertaken to identify any measures that would help in future cases.

Conclusion
One of the most challenging scenarios in obstetric care occurs when a pregnant patient refuses recommended medical treatment that aims to support her well-being, her fetus’s well-being, or both. Such cases call for an interdisciplinary approach, strong efforts at effective medical communication, and resources for the patient and the health care team. The most suitable ethical framework for addressing a pregnant woman’s refusal of recommended care is one that recognizes the interconnectedness of the pregnant woman and her fetus but maintains as a central component respect for the pregnant woman’s autonomous decision making. This approach does not restrict the obstetrician–gynecologist from providing medical advice based on fetal well-being, but it preserves the woman’s autonomy and decision-making capacity surrounding her pregnancy. Pregnancy does not lessen or limit the requirement to obtain informed consent or to honor a pregnant woman’s refusal of recommended treatment.

References


