End-of-Life Decision Making

ABSTRACT: Obstetrician–gynecologists care for women throughout their lifespans and are in an ideal position to have ongoing discussions with healthy patients about their values and wishes regarding future care and to encourage them to complete an advance directive for health care. In addition, situations may arise in which obstetrician–gynecologists need to participate in end-of-life care. When end-of-life decisions need to be made while a woman is pregnant, the level of ethical complexity often is increased. The purpose of this Committee Opinion is to discuss ethical issues related to end-of-life care, historical and legal constructs, patient–physician communication, intradisciplinary and interdisciplinary collaboration, and educational opportunities pertinent to obstetrician–gynecologists and other providers of women’s health care.

Obstetrician–gynecologists care for women throughout their lifespans. Situations may arise in which obstetrician–gynecologists need to participate in end-of-life care. For example, the obstetrician might care for a pregnant woman who suffers a tragic accident, succumbs to a critical illness, or experiences a pregnancy-related life-threatening event. The gynecologist may diagnose cancer or another life-threatening disease in a woman and then treat and monitor her. In these cases, the patient–physician relationship calls for guidance to patients that respects their dignity as they face end-of-life decisions. Many ethicists and physicians have written about the goal of a “good death” for the patient. To achieve a “good death,” the health care team works together so that the dying process for the patient will be family and health care provider supported; focused with attention to physical, emotional, and spiritual needs; rational and appropriate in the use of life-extending technologies; free of adverse events; and attentively supportive to reduce suffering (1–3). When end-of-life decisions need to be made while a woman is pregnant, the level of ethical complexity often is increased. The purpose of this Committee Opinion is to discuss ethical issues related to end-of-life care, historical and legal constructs, patient–physician communication, intradisciplinary and interdisciplinary collaboration, and educational opportunities pertinent to obstetrician–gynecologists and other providers of women’s health care.

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

• Good end-of-life care is an intradisciplinary and interdisciplinary effort. Specially trained palliative care physicians, nurses, social workers, counselors, and religious or spiritual advisers are integral partners in end-of-life transitions, and partnering with these professionals is encouraged when they are available.

• The obstetrician–gynecologist is in an ideal position to have ongoing discussions with healthy patients about their values and wishes regarding future care and to encourage them to complete an advance directive for health care by describing their wishes in writing (a “living will”) and designating a surrogate decision maker for medical decisions. Ideally, the physician’s office is the preferred setting for such a discussion rather than the hospital at a time of crisis, and discussion early in the course of prenatal care or
during well-woman treatment is recommended. In practice, however, this discussion often occurs when unanticipated situations arise or when a potentially life-threatening condition is discovered.

- In instances of disagreement, respect for a woman’s autonomy guides the manner of care that she receives at the end of her life. The woman’s wishes and values should be respected, as relayed by her surrogate decision maker if she has not previously voiced or documented any wishes and does not have the capacity to make her own health care decisions.
- If decisions made by a woman or made on her behalf by her surrogate decision maker cause the physician to experience significant moral distress or ethical conflict, the physician has the right to transfer care to a physician who has more expertise and is more comfortable with these choices.
- The provision of optimal end-of-life care allows the physician to refrain from the use of life-extending technologies that are no longer beneficial or that may impose harm on the patient and should include consideration of palliative care efforts.
- On rare occasions, physicians may be asked by a patient for assistance in hastening the time of her death. Often these requests are related to feelings of lack of control, unrelied pain, or emotional angst about the dying process and may be seen as an opportunity to open a conversation. When this occurs, enhanced palliative care efforts, expert pain management, and counseling are all appropriate to address the patient’s physical suffering and emotional distress, and the physician is encouraged to use these resources.
- The principles articulated in this document should be honored regardless of whether or not a woman is pregnant.

**Patient–Physician Relationships and End-of-Life Care**

Obstetrician–gynecologists encounter patients at the end of life in emergent and expectant situations. The end of life may come tragically and unexpectedly in the very young or as a natural trajectory in the life of an older woman. Obstetrician–gynecologists’ long-term relationships with patients often engender a level of trust that is valued by the patient. In some cases, the obstetrician–gynecologist may be the only physician the patient has seen regularly through much of her life.

For these reasons, the obstetrician–gynecologist is in an ideal position to have ongoing discussions with healthy patients about their values and wishes regarding future care. Because a patient’s wishes regarding care may change over time and under conditions of illness or life-altering events, such as pregnancy, these conversations may include an occasional review of values and goals.

**Ethical Principles and Ethics Resources**

Adherence to basic ethical principles is critical in care for the dying. Beneficence requires that the patient not be abandoned and that desired attempts at a good quality of life be supported. The principle of nonmaleficence asks physicians to be conscious of situations in which the burdens of technological support outweigh the hoped-for benefits. Ideally, justice aims to provide access to excellent end-of-life services to all patients regardless of payment abilities, whether inpatient or outpatient, with timely referral to palliative care and hospice services. Justice in health care also calls for physicians to consider the cost of the interventions they are recommending and whether the interventions are efficacious (4). The provision of optimal end-of-life care allows the physician to refrain from the use of life-extending technologies that are no longer beneficial or that may impose harm on the patient and should include consideration of palliative care efforts.

Respect for autonomy dictates that the choices of the patient with decision-making capacity be respected. Respect for culture allows that death may be viewed in the context of a variety of spiritual or religious traditions and that efforts be made to understand and respect the cultural mores of the patient and her family. Cultural issues may include with whom one communicates within the family, whom the patient looks to for advice and decision making, how the patient feels about the use of pain medications, and how suffering is understood (5–7). When a patient lacks the capacity to make health care decisions, the health care provider may be faced with conflicts between surrogate decision makers and cultural expectations. For example, the health care provider may experience an ethical dilemma when interacting with cultures in which the husband makes decisions that the wife may not desire. The patient’s religious or spiritual adviser and the hospital or local ethics committee may prove helpful in coming to an agreed-upon plan of care. The physician needs to balance respect for culture with the College opinion that informed consent from the patient herself is a vital component of health care (8).

The Joint Commission requires all U.S. hospitals to have “a process that allows staff, patients, and families to address ethical issues or issues prone to conflict” (9). This assistance is most commonly provided by an ethics committee but also can be provided by an ethics consultant or consultation service. Whatever the process, it needs to be readily accessible to patients and their surrogate decision makers as well as staff, physicians and other licensed independent practitioners, and managers. Some health care facilities have staff that offer “moral distress” consults as a subset of, or adjunct to, formal ethics consultation (10, 11). The assistance of trained palliative care physicians, counselors, nurses, social workers, and religious or spiritual advisers can help physicians and patients work through an agreed-upon plan of care. A hospital ethics
consultant or ethics committee can assist in allowing all parties to voice their wishes and concerns, frame the issues, and attempt to resolve disputes.

**Advance Directives and End-of-Life Care Planning**

Since 1991, Medicaid-participating and Medicare-participating health care institutions have been required to inform all adult patients of their rights to make decisions concerning medical care, including the right to formulate an advance directive. The obstetrician–gynecologist is in an ideal position to have ongoing discussions with healthy patients about their values and wishes regarding future care and to encourage them to complete an advance directive for health care by describing their wishes in writing (a “living will”) and designating a surrogate decision maker for medical decisions. Ideally, the physician’s office is the preferred place for such a discussion, rather than in the hospital at a time of crisis, and discussion early in the course of prenatal care or during well-woman treatment is recommended. In practice, however, this discussion often occurs when unanticipated situations arise or when a potentially life-threatening condition is discovered.

An advance directive is the formal mechanism by which a patient may express her values regarding her future health status. The advance directive includes the appointment of a designated surrogate decision maker. The terms health care proxy, health care agent, and surrogate can be used interchangeably. The term surrogate decision maker is used in this Committee Opinion and refers to the person designated by the patient to represent her wishes and values when she is no longer capable of doing so. The legal instrument by which this role is established is a durable power of attorney for health care, and this term sometimes also is used to refer to the person who serves as the patient’s surrogate decision maker.

The advance directive may take the form of a proxy directive, an instructional directive, or both. Proxy directives, such as the durable power of attorney for health care, designate a surrogate to make medical decisions on behalf of the patient who is no longer competent to express her choices. An advance directive is a valid document when signed and witnessed (with notarization in states that require it). In the advance directive, a patient is asked to designate how she wishes to be cared for at the end of her life should she lack decision-making capacity and be unable to make her wishes known at that time. Components of the directive may include specific preferences for the level of resuscitative efforts at the end of her life, the kinds of medical therapies and technological support desired or not desired, and the designation of a surrogate decision maker to make health care decisions when the patient is no longer able to do so. The advance directive should be placed in the medical record and shared easily between the office, clinic, and hospital. Additionally, it is recommended that women of childbearing age be assisted in considering how a possible future pregnancy may influence their directives. Recommending to the patient that all decisions made be discussed with family or designees may ensure that those chosen as surrogate decision makers will be willing to represent the patient’s designated wishes and values. The advance directive can be amended and changed at any time by the patient as long as she has the capacity to make health care decisions.

Providing templates of advance directive documents in the office can guide the physician in initiating end-of-life conversations. Several organizations have created documents to assist patients in creating an advance directive. An example of such a document is the Five Wishes document, provided by Aging with Dignity, which has been translated into 26 languages and has been used to offer explanations of the choices that one might make at the end of life (12). Some patients may wish to consult a spiritual or religious adviser when filling out an advance directive should they have questions related to how their faith might view end-of-life issues.

Physician orders for life-sustaining treatment, commonly known as POLST, complement advance directives. The physician orders for life-sustaining treatment form differs from an advance directive because it is an order set rather than a list of descriptions that the advance directive provides. These forms go by other names in some states, such as medical orders for life-sustaining treatment. These very short and direct forms can be on paper or electronic, and they state what kind of medical treatment should be provided toward the end of the patient’s life. Signed by a physician and the patient or her surrogate decision maker, this type of document is an order set that travels with the patient. The document, which reflects the decisions that may appear in an advance directive, gives patients more control over their lives should they become seriously ill. The physician orders for life-sustaining treatment document is now being used throughout many states in the nation.

**Organ Donation**

Physicians who care for dying patients may wish to have further knowledge about organ donation. In 1984, the U.S. Congress passed the National Organ Transplant Act, establishing the Organ Procurement and Transplantation Network to maintain a national registry for organ matching. The act also called for the network to be operated by a private, nonprofit organization under federal contract. The United Network for Organ Sharing in Richmond, Virginia, was chosen. This organization maintains a database of living and deceased individuals from whom organs have been obtained for transplantation, individuals who are candidates for organ transplantation, and individuals who have received transplanted organs. Within the United Network for Organ Sharing, there are numerous national organ procurement organizations. Each U.S. hospital is affiliated with one of these agencies (13).
When a patient may be approaching death, the assigned hospital staff member notifies the local organ procurement organization. A representative of the organ procurement organization is responsible for assessing whether the potential donor is suitable and for discussing this with the family. The representative has special training for such discussions. Physicians should have education on this subject if they wish to initiate or participate in the organ procurement discussion (14). Some feel that it is not appropriate for members of the hospital staff to discuss organ donation for fear that the family may lose their trust in the physician. Should the family bring this up, the physician should invite the expert from the donation headquarters to come in to discuss this subject (13).

Care as the End of Life Approaches
Determining treatment goals may become more difficult when the discussion occurs after an illness has been diagnosed or when the patient is ill and in the hospital. Physicians may need to provide more in-depth education to explain future trajectories and to answer questions about life, death, suffering, and pain relief that may originate with sources outside of medicine, such as in the lay press or cultural beliefs.

The woman and her physician often are in accord as to their goals, whether those goals involve making all efforts to save her life or moving toward palliative care. Physicians and nurses may experience moral distress if they are not able to provide the type of care that they feel is optimal (15). Such moral distress may occur when the wishes of the physician are not in accord with the wishes of the patient, the patient’s family, the legal system, or the hospital administration (10, 11). This may happen when a woman desires that all technological efforts be made to extend her life, but the physician and health care team recognize that further life-extending therapies are no longer of medical benefit or could impose harm. Women and their families may need assistance to reframe an unrealistic hope for a cure into a hope for improved quality of life and then a “good death.” The physician also may experience moral distress when a woman desires the transition to solely palliative care, but the physician does not feel it is time to cease life-sustaining or disease-fighting therapies.

In instances of disagreement, respect for the woman’s autonomy guides the manner of care that she receives at the end of her life (16–18). It should be noted that although the right to refuse care is respected with very few caveats (eg, mandatory reporting issues), there may be limits to the right to demand care, depending on available personnel and resources. The woman’s wishes and values should be respected, as relayed by her surrogate decision maker if she has not previously voiced or documented any wishes and does not have the capacity to make her own health care decisions. If decisions made by a woman or made on her behalf by her surrogate decision maker cause the physician to experience significant moral distress or ethical conflict, the physician has the right to transfer care to a physician who has more expertise and is more comfortable with these choices (16–18). Some states are now allowing unilateral “do not resuscitate” orders when the physician assesses that the resuscitation effort would be harmful rather than therapeutic (19).

Physicians may wish to note the newer term, “allow natural death,” that has been adopted in many facilities in the United States to replace the term “do not resuscitate” (20). This term redirects the conversation from discussing with patients and families what care will not be delivered toward discussing what care will be delivered. Patients and families are reassured that pain and symptom management will be the utmost priority, that no uncomfortable tests or interventions will be allowed, that doors will be open to visitors, and that spiritual and social services will be available at the bedside.

On rare occasions, physicians may be asked by a patient for assistance in hastening the time of her death. Often these requests are related to feelings of lack of control, unrelieved pain, or emotional angst about the dying process and may be seen as an opportunity to open a conversation. When this occurs, enhanced palliative care efforts, expert pain management, and counseling are all appropriate to address the patient’s physical suffering and emotional distress, and the physician is encouraged to use these resources.

Kathryn L. Tucker, a leading advocate in the end-of-life choice movement, believes that “provision of aid in dying does not constitute assisting a suicide or euthanasia” (21). Aid in dying, she writes, “is a practice with growing support in the public and medical and health policy communities and is likely to become more widely requested in the future...A clinician cannot be compelled, [however,] to provide a treatment that conflicts with his or her personal values” (21).

As of the time of publication of this document, assistance in dying is legal in several states in the United States and in some European nations. Statistics from the United States show that where assistance in dying is legal and patients have asked for this assistance, not all use it to hasten their deaths (22, 23). Patients living in these states report that this option gives them a sense of control, and data show that palliative care efforts increase (22). The public health departments in some of the states in which assistance in dying is legal, such as in Oregon, Washington, and Vermont, offer patient request forms and physician forms to be used. In addition, patients’ hastening of their dying has trended away from the use of physician-prescribed medications and toward the patient’s voluntary cessation of eating and drinking (24, 25).

As the therapies evolve from curative efforts to solely comfort measures, the patient may remain in the hospital or be cared for in her home, in a long-term care facility, or in a hospice or palliative care unit. Patients may feel
A pregnant woman’s right to provide informed consent or refusal should not be contingent upon the presence or absence of terminal illness, the agreement of family members, or the approval of physicians or hospital administrators. In the case of In re A.C. (30), the District of Columbia Court of Appeals held that a terminally ill pregnant woman had the right to make health care decisions for herself and for her fetus (31, 32). The hospital ethics consultant or ethics committee serves as a resource to bring greater clarity, if not consensus, to any previously indicated wishes of the woman, her surrogate decision maker’s attempts to express her wishes, the family’s wishes, and the recommendations of the clinicians.

Posthumous Reproduction

The obstetrician–gynecologist who provides end-of-life care may need to consider the ethics of the posthumous use of gametes and embryos for reproduction. In the course of fertility treatment and assisted reproduction, reproductive tissue, including oocytes, sperm, and embryos, may be cryopreserved. Patients are strongly encouraged to state in writing their decisions regarding the disposition of their stored gametes and embryos in the case that one or both intended parents die before the gametes or embryos are used. Such decisions should be made at the time of the initial treatment. Options include transferring dispositional control of the gametes or embryos to a surviving partner or to a third party, donating them to research, or discarding them. Such requests are normally honored. Occasionally, family members or surrogate decision makers may ask physicians to invasively procure posthumous gametes for reproductive purposes. The American Society for Reproductive Medicine states that a request to obtain oocytes after a woman’s death without the woman’s prior consent or known wishes need not be honored. Readers are directed to the organization’s full ethics statement for details (33).

Conclusion

Good end-of-life care is an intradisciplinary and interdisciplinary effort. Specially trained palliative care physicians, nurses, social workers, counselors, and religious or spiritual advisers are integral partners in end-of-life transitions, and partnering with these professionals is encouraged when they are available.

Obstetrician–gynecologists are in a unique position to encourage women to formulate advance directives. All patients appreciate the support of their physicians when difficult situations arise, and families remember how their loved one was treated by the health care team. Communicating honestly and openly, being receptive to differing views, and appreciating cultural differences that may determine how death is understood will help physicians to make end-of-life care a valued part of their work. Use of ethics consultation and the interdisciplinary team provides a “village” of caregivers for the patient.

End of Life and Pregnancy

The College believes that the principles articulated in this document should be honored regardless of whether or not a woman is pregnant. Some state laws, however, are not congruent with this position and, in some cases, specify that with or without clearly stated end-of-life wishes from a pregnant woman, additional consideration should be given to the fact that she is known to be pregnant. Physicians are encouraged to support a pregnant woman’s autonomy and decisions whenever legally possible. If the woman has not previously voiced or documented any wishes or values and is unconscious or lacks capacity, her surrogate decision maker will be her voice. The health care facility should not attempt to contravene her wishes and values, whether she voices them or they are relayed by a surrogate decision maker. Every attempt should be made to respect the wishes and values of a woman who is conscious and who has the capacity to make health care decisions. A resource for the state laws regarding pregnancy and advance directives can be found at http://statelaws.findlaw.com/estate-planning-laws/living-wills/.

Recently, some pregnant women who are dead according to brain death criteria have been technologically supported in an attempt to allow further maturation and delivery of the fetus. Such technological support may be ethically permissible if the surrogate decision maker for such a pregnant woman requests an attempt at additional fetal development on her behalf (28, 29). It is unethical to attempt to coerce a surrogate decision maker into agreeing to technical support that is contrary to the woman’s treatment preferences or the surrogate decision maker’s interpretation of the wishes of the patient.
Physicians should be true to their own values as well, never ceasing to acknowledge the dignity of the dying patient and provide support to her and her loved ones, but asking other colleagues to step in when the situation warrants. The College recognizes and respects the depth of concern in the physician who must balance care for the dying woman, possibly a fetus, and the extended family, and. The College encourages those who provide care to dying patients to be aware of the burdens it may place on themselves and be sensitive to their need for self-care.

References


