Ethical obligations in fertility treatment when intimate partners withhold information from each other: an Ethics Committee opinion

Ethics Committee of the American Society for Reproductive Medicine

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Clinicians should encourage disclosure between intimate partners but should maintain confidentiality in cases where there is no prospect of harm to the partner and/or offspring. In cases where a member of a couple refuses to disclose relevant health information to the other partner and there exists a risk of harm to the unaware partner and/or offspring, clinicians may refuse to offer care and should decline to treat if full informed consent is not possible because of the lack of disclosure. This document replaces the previously published document of the same name, last published in 2018. (Fertil Steril® 2024;121:428–33. ©2024 by American Society for Reproductive Medicine.)

El resumen está disponible en Español al final del artículo.

Key Words: Protected health information, informed consent, assisted reproduction, disclosure, ethics

KEY POINTS

- Physicians should encourage couples presenting for fertility treatment to disclose to one another relevant information that can affect their reproductive decision-making.
- Ideally, the reproductive dyad should sign a waiver allowing for their physician to share all clinically relevant information with both reproductive partners. This would include information provided by either member of the couple as well as information discovered during evaluation and treatment. The waiver should set forth a clinic's policy on disclosure of clinically relevant information, including disclosure in the absence of the patient or partner's further consent. If the members of the dyad are unwilling to sign the waiver, physicians should explain any limits to care, including the possibility that they will be unable to provide care if protecting the confidentiality of 1 partner precludes informed consent on the part of the other partner.
- Cases may arise in which a patient asks a physician to withhold clinically relevant information from their intimate partner. In such cases, physicians are both ethically and legally bound to maintain patient confidentiality, except as otherwise provided by law.
- When confidentiality cannot be maintained (e.g., because of state reporting requirements), the patient should be told this, ideally before the information is obtained. In such situations, it is ethically permissible for the physician to decline care.
- In cases where the lack of disclosure precludes fully informed consent or has the potential to harm the patient, their intimate partner, or their offspring, physicians should strongly encourage disclosure. If the patient declines to allow for such disclosure, physicians are ethically obligated to decline the provision of reproductive care.
- The lack of information sharing between intimate partners can impede a physician's ability to obtain fully informed consent from both members of the couple. Potential impacts on informed consent include the physician's inability to fully discuss the range of possible treatment options as well as the risks and benefits of the proposed treatment. In such cases, physicians may proceed or decline to offer treatment and should make such judgments in a nondiscriminatory fashion and without bias, taking into consideration potential risks to the partner and potential offspring and potential liability risks to the physician if they proceed without being able to obtain fully informed consent.
- In cases where the information, if disclosed, may be relevant to the partner's decision whether to undergo fertility treatment, the physician should also strongly encourage disclosure between intimate partners. This includes situations in which fertility treatment is required that could otherwise have been avoided if certain information had been shared.

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When couples present for fertility care, they usually do so as a unit whose interests are aligned. Ideally, couples present for evaluation and treatment having already shared relevant information often with one another regarding their reproductive health and risks. Fertility care providers routinely advise couples that they are equal members of the treatment dyad and encourage open communication and honesty. In fact, several physicians ask that couples allow information to be shared freely between the physician and each of them, even when this information pertains to their partner. As a practical matter, providers should consider requesting that patients with partners sign a waiver of confidentiality regarding all information that is material to the provision of fertility care services. Such a waiver would permit a provider to share relevant information with the couple as needed in the context of the treatment being sought. This would include both information shared by either member of the couple and information that is discovered during the medical evaluation and treatment. If a couple, or a member of a couple, declines to sign such a waiver, physicians may decline to provide treatment on the basis of concerns that fully informed consent cannot be assured.

Situations can arise in which a couple presents to a physician for treatment and a member of the couple shares information with the physician that they ask not to be shared with their partner. In some cases, this information is relevant to the medical management of 1 or both members of the couple and may affect treatment options, outcomes, and risks to the partner or any resulting children. In these cases, the physician may have serious reservations about initiating or continuing treatment for partners who do not disclose to one another. This committee opinion will address various situations that may arise and the responsibility of the physician to each member of the couple individually and to the couple as a whole in such cases.

Physicians have several options when asked by a patient not to disclose pertinent information to the patient's partner. One is to encourage disclosure but to continue treatment in the absence of disclosure, being careful not to share any information that they have been asked to keep in confidence. The second is to require disclosure between the partners before moving ahead with treatment and to decline to treat a couple if they refuse to share information with each other that the physician judges material to their care. In either case, an emphasis on counseling from a trained mental health professional with expertise in the complex psychosocial issues faced by fertility patients should be offered and encouraged and may help couples feel more comfortable sharing mutually relevant information with one another (1).

When relevant clinical information is not freely shared between intimate partners, this may impact informed consent. The physician's ability to obtain informed consent from the couple, and particularly from the member of the couple from whom information has been withheld, may be impeded. Such cases prove difficult because physicians may be limited in their ability to explain why a given treatment is not offered, another treatment is recommended, or the recommended treatment is not optimal. Particularly when the lack of disclosure between intimate partners limits the ability to obtain fully informed consent from all stakeholders, free information sharing should be strongly encouraged. Physicians should decline to provide treatment when fully informed consent for the proposed treatment itself cannot be given by both partners because 1 partner would be subjected to risks and treatment options that cannot be disclosed without violating the confidentiality of the withholding partner.

Importantly, in some cases, there may be consequences of disclosure for the safety or well-being of the intimate partner. This is particularly so for individuals who may face violence, abuse, or rejection. As such, disclosure requires great sensitivity and should be accomplished in the manner most preferred by the patient while ensuring that it does not cause the patient harm.

Several broad categories of harm can occur when intimate partners fail to disclose material information regarding themselves. These will be discussed individually in the following sections. Many of the clinical examples provided in this document focus on communicable diseases because the lack of disclosure of disease status may be preferred by 1 partner but have implications for the reproductive decision-making of the other partner. The intent of these examples is not to stigmatize infectious diseases, which are common among sexually active adults (2). In cases of infectious disease, physicians should be familiar with and abide by state and federal reporting requirements and should make these obligations clear to their patients.

WHEN NONDISCLOSURE LEADS TO THE RISK OF PHYSICAL HARM TO THE INTIMATE PARTNER

If the provider of the sperm carries an infectious disease, there can be a risk of physical harm to the partner when fertility treatments involve using the infected individual's sperm. Although strategies exist to lower significantly—and perhaps almost eliminate—transmission of human immunodeficiency virus (HIV), no strategy can guarantee with absolute certainty that disease transmission will not occur (3, 4). Hepatitis C and hepatitis B are other infectious diseases that can be theoretically transmitted through reproductive treatment. It is recommended that screening for infectious disease, when available, be universal and routine, as effective treatments for many exist, and consideration of alternative treatment modalities can prevent transmission to both sexual partners and offspring.

In a previous Ethics Committee opinion (3), the American Society for Reproductive Medicine has taken the position that it is permissible to offer infertility treatment to HIV-infected persons if the clinic has the necessary facilities and the partners are willing to use the recommended methods of risk reduction. In that opinion, the Committee stated: "Informed consent in the medical setting requires that physicians disclose any information material to a person's decision to undergo or refuse treatment."

By contrast, cases in which donor gametes are used, or in which a female but not the male partner has an infectious disease and artificial insemination is used, do not place the partner at risk of infection. However, a female who carries an

infectious disease should be strongly encouraged to disclose this information to her partner given the potential risks of vertical transmission to the offspring as well as transmission to the partner if they are sexually intimate (3). In this situation, clinicians may refuse to provide care because the nongestational parent would not be aware that treatment leading to pregnancy places the offspring at risk of acquiring an infectious disease because this may violate their ability to provide fully informed consent, as detailed in the following section.

WHEN NONDISCLOSURE IMPEDES A PARTNER'S ABILITY TO PROVIDE FULLY INFORMED CONSENT

A particular example in which a partner may not be able to fully participate in informed consent but does not face any physical risks to themselves is a scenario in which harm to the offspring may occur on the basis of genetic risks that a partner may not wish to share. For example, a woman may know that she is a carrier of an X-linked disorder such as fragile X. She may not wish to disclose the fact that her offspring could be affected by fragile X to her partner. Similar situations arise when one of the partners is a carrier of Huntington disease or breast cancer gene, conferring risk on the children without the knowledge of the other partner. In these situations, the uninformed partner may have made different reproductive decisions to avoid these risks to their offspring. Such decisions could include the use of donor gametes, preimplantation genetic testing, adoption or opting not to have children.

Another situation is the potential for transmission of an infectious disease to the offspring. For example, if the individual carrying the pregnancy is infected with HIV, hepatitis B, or hepatitis C, there are risks of transmission to the offspring that the other partner may deem too high to proceed with pregnancy were they to be informed of this potential risk.

In some cases, 1 or both partners may have health conditions that they have not disclosed to the other. These may include previous treatment for cancer or for other conditions that have played a role in the need for infertility care. Here, the primary risk is that a partner may undergo the fertility care without knowing that he/she has a greater-than-average risk of being left to raise a child on his or her own. In a previous opinion, the Committee has taken the position that it is permissible to provide infertility care to patients with potentially life-limiting illnesses. The Committee wrote: "Concerns about the welfare of resulting offspring, whether due to an expected shortened lifespan of the parent or effects of cancer or infertility treatment (in the present state of knowledge) ordinarily are not a sufficient reason to deny cancer patients assistance in reproducing" (5). This discussion assumed that both partners were aware of the possibility of a partner's earlier death and voluntarily took on the risk of raising a child alone. Here, where the partner is not disclosing his or her condition, the other may be assuming a risk of raising a child alone that they would prefer to avoid.

There are also situations in which pregnancy is risky to the patient because of an underlying medical condition and the risk of morbidity or mortality is increased over the baseline risk that pregnancy presents. Such cases occur, for example, in a woman with Turner syndrome whose partner may not be aware that carrying a pregnancy is associated with a risk of aortic dissection and death. Knowing this, the partner may have chosen to avoid initiating a pregnancy with her in favor of choosing to create a family with a gestational carrier or via adoption. The lack of disclosure may lead to a situation where he faces the consequences of being a single father because of maternal death. Certainly, such situations also increase the risk of pregnancy and neonatal complications, including preterm birth. Disclosure between intimate partners should be strongly encouraged in these cases.

WHEN NONDISCLOSURE OF INFORMATION CONCEALS THE INDICATION FOR FERTILITY TREATMENT

There are also cases in which a partner does not want to disclose information that could have enabled the couple to avoid the need for some or all infertility treatments. One example is a situation in which the use of anabolic steroids or testosterone leads to a low or absent sperm count, necessitating the use of intrauterine insemination or in vitro fertilization (IVF) that would be otherwise unnecessary. Other scenarios could include an individual who is sterile due to a previous vasectomy or tubal ligation. Individuals may not wish to disclose this information to their partner or to consider the possibility of reversing the vasectomy or the tubal ligation before undergoing fertility treatment. In such cases, disclosure should be strongly encouraged between intimate partners. However, for the affected couple, the only way for conception to occur given the present circumstances is with assisted reproduction, and the parties would be aware of the risks and benefits of fertility treatment. Although, ideally, the information should be shared, clinicians may choose to offer fertility services in the absence of disclosure of the surgical etiology of the infertility. Under these circumstances, partners are aware of the need for assisted reproduction and can be fully counseled regarding the risks of the procedure; they only lack knowledge of the reason why the procedure is needed.

In other cases, a partner may not have disclosed to the other previous sexual abuse, leading to inability to have intercourse. Perhaps psychological treatment could help that individual achieve normal sexual function and avoid the need for fertility treatment. However, the partner in such a case is aware of the existence of the inability to complete intercourse and the need for fertility treatment. Both partners can provide informed consent regarding the proposed treatment modality without breaking the confidentiality of the individual who prefers not to disclose the etiology of the inability to have intercourse. Again, an emphasis on counseling from a trained mental health professional with expertise in the complex psychosocial issues faced by fertility patients should be offered and encouraged.

Another situation in which the patient may not wish to share the etiology of infertility with her partner is in cases

of Asherman syndrome due to a previous pregnancy termination. The partner may be morally or otherwise opposed to abortion and would then view his partner differently causing harm to the relationship.

WHEN DISCLOSURE OF INFORMATION MAY LEAD TO HARM IN THE RELATIONSHIP

Yet another scenario is a case in which the male partner has a congenital bilateral absence of the vas deferens and his partner has conceived a child that he believes to be genetically his. In the course of a secondary infertility evaluation, the reality that the pregnancy could not have been achieved without assistance will likely become apparent. With the absence of a specific directive by the male patient to withhold relevant findings from the evaluation, the clinician is obligated to fully inform the male of his medical circumstances. This duty holds regardless of whether the male partner inquires if the previous child could be his genetic offspring. This duty to disclose the male's medical circumstances also holds even when the female partner requests that the physician not reveal the means by which she previously conceived. There is significant concern in such cases that, beyond emotional harm, the woman or child may experience psychological or physical harm or abuse after such disclosures, and great care should be taken by the clinician to be sensitive to this possibility.

ETHICAL ANALYSIS

Respect for patient confidentiality is a core principle of bioethics. Patient autonomy requires that individuals should be able to choose whether to permit others to know information about their health. Confidentiality also is critical for patients to trust providers and be willing to share information with them. As such, a standard recommendation when patients wish not to disclose information is that confidences should be kept. If there are strong reasons favoring disclosure to prevent harm to the patient or others, the patient should be counseled about the advisability of disclosure. A related recommendation is that if confidentiality cannot be kept (e.g., because of state reporting requirements), the patient should be told this, if at all possible before the information is even obtained. Thus, the recommendation is that patients be counseled about the need for disclosure of positive HIV tests before HIV tests are performed. A further reason for protecting confidentiality is that disclosure may be harmful to the patient if it results in loss of important benefits, damage to relationships, or violence. Confidentiality becomes especially problematic when it is associated with risks to others (6–9).

In the cases outlined earlier, the following risks were identified:

- The partner may face physical risks due to the potential of disease transmission or the need to undergo procedures that he or she may choose to avoid.
- The partner may face risks to offspring that he or she may choose to avoid.
- The partner may face a higher risk of becoming a single parent, when he or she would prefer to remain childless rather than raising a child alone without the other partner.
- The partner may remain ignorant of the information that he or she would regard as important in the context of the relationship.
- The patient may face physical or emotional abuse by the partner.
- Treatment options may be impacted or eliminated.

These risks are of differing strengths when weighed against the importance of confidentiality and reasons supporting nondisclosure.

If a partner faces physical risks from treatment that are not disclosed because of their partner's insistence on confidentiality, informed consent is not possible. The partner undergoing treatment would face undisclosed but significant risks. In the Committee's opinion, it would be unethical to provide the treatment under conditions in which informed consent cannot be obtained. The clinician should advise the nondisclosing partner of the importance of disclosure for treatment to proceed. If the nondisclosure is of information that may allow infertility treatment to be avoided, informed consent to infertility treatment is possible; however, informed consent regarding the range of options and the etiology of the infertility is not. Because there is a possibility that the treatment may be avoided, clinicians may ethically decline to provide treatment in such cases.

In the case of risks to offspring, the nondisclosing partner does not face physical risks to himself or herself. However, the other partner has extremely strong interests in knowing about the risks to offspring and participating in decisions about whether to pursue other options.

In cases in which a patient is at increased risk of negative health effects or pregnancy-related risks resulting from fertility treatment, personal risks may result in the partner being left to raise children on their own. Although there are cases in which such risks are higher than average due to specific medical determinants, such risks are ones that anyone may take in having children. Because the unaware partner has a strong interest in participating in the decision about whether to undertake this risk, clinicians should strongly encourage disclosure (10). Clinicians should also advise the patient that depending on the clinical course, the confidence may be difficult to keep in any event. Assuming that the treatment is permissible in spite of the risks (11), clinicians may provide treatment in these cases, especially if the reasons for nondisclosure are strong. An example would be the possibility of failure of the relationship if the disclosure were made.

If the nondisclosure results in economic costs—the costs of treatment—that may be avoided, disclosure should be encouraged. For example, a female with a previous tubal ligation will require IVF for tubal factor infertility. Knowing the reason for the tubal infertility will not change the need for the treatment. Likewise, a male with a previous vasectomy will need either a vasectomy reversal or sperm extraction and likely IVF. Again, the economic realities are not affected by the etiology of the infertility. In such cases, the partner

with incomplete knowledge regarding the cause of the infertility is, nevertheless, fully aware of the costs and can choose whether to participate in the infertility process. Although disclosure should be encouraged in these cases, it is permissible for the clinician to provide treatment.

In cases in which the nondisclosure is of information that the partner may regard as material to the relationship, such as the effects of a previous abortion, the reasons for nondisclosure are likely extremely strong. Whether to share this information, which is not medically relevant, should be an issue for the partners themselves. Clinicians should provide care in this case and keep the confidence.

CONCLUSION

Clinicians should encourage partners to share information with one another. Clinicians should refuse to provide care when appropriate informed consent of either partner regarding the proposed treatment may not be assured. Clinicians may refuse to provide care when the explanation of the range of options cannot be fully provided to one of the partners due to the other partner withholding relevant information about the need for the care. When an individual has strong interests in knowledge that his or her partner chooses to withhold, for example, to avoid harm in the offspring or in cases where an increased risk of death or disability from fertility treatment or pregnancy exists, clinicians should strongly encourage disclosure and may decline to provide fertility services. In cases in which disclosure would not change the proposed treatment and the treatment will not cause harm to either the partner or their offspring, clinicians may provide care in the absence of full disclosure between the intimate partners.

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Obligaciones éticas en tratamientos de fertilidad cuando las parejas íntimas retienen información propia: dictamen del Comité de Ética

Los médicos deben fomentar la divulgación entre parejas íntimas, pero deben mantener la confidencialidad en los casos en los que no exista perspectiva de daño a la pareja y/o a la descendencia. En los casos en que un miembro de la pareja se niegue a revelar información de salud relevante a la otra pareja y existe un riesgo de daño a la pareja inconsciente y/o a su descendencia, los médicos pueden negarse a ofrecer atención y debe negarse a tratarlo si no es posible obtener un consentimiento informado completo debido a la falta de divulgación. Este documento reemplaza al anterior Documento publicado del mismo nombre, publicado por última vez en 2018.