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

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Clinicians should encourage disclosure between intimate partners but must maintain confidentiality in cases where there is no prospect of harm to the partner and/or offspring. In cases where one 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 due to lack of disclosure. (Fertil Steril® 2018;110:619–24. ©2018 by American Society for Reproductive Medicine.)

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KEY POINTS

- Clinicians 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 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 one partner precludes informed consent on the part of the other partner.
- Cases may arise in which a patient shares information with the clinician and asks that this information not be shared with 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 kept (for example, because of state reporting requirements), the patient should be told this, ideally before the information is even obtained. In such situations, it is ethically permissible for the clinician to decline care.
- In cases where lack of disclosure can cause harm to the patient, their intimate partner, or their offspring, the clinician should strongly encourage disclosure.
- When patients refuse to disclose information to their intimate partners, and proceeding with fertility treatment could cause harm to the patient, partner, or offspring, clinicians may refuse to offer reproductive care.
- Clinicians are ethically obligated to decline to provide care when the circumstances are such that fully informed consent for the proposed treatment cannot be given because the patient would be subjected to risks that cannot be disclosed without violating clinician-patient confidentiality.
- 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, clinicians may proceed or decline to offer treatment, and should make such judgments in a non discriminatory fashion and without bias.
• In cases where the information, if disclosed, might be relevant to the partner’s decision whether to undergo fertility treatment, the clinician 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.

INTRODUCTION

When couples present for fertility care, they usually do so as a unit whose interests are aligned. They have shared relevant information often with one another regarding their reproductive health and risks. Fertility care providers routinely advise couples that they are both part of the treatment dyad, and encourage open communication and honesty. In fact, many clinicians ask that couples allow information to be shared freely between the clinician and each of them, even when this information is regarding their partner. As a practical matter, providers should consider requesting their 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 one member of a couple, declines to sign such a waiver, the physician may deny treatment if he or she is unable to ensure fully informed consent in the absence of unobstructed sharing of mutually relevant information.

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

The clinician has 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 he or she has been asked to keep in confidence. The second is to require disclosure between the partners prior to moving ahead with treatment, and to decline to treat a couple if they refuse to share information with each other that the clinician judges material to their care. In either case, counseling should be offered and may help couples feel more comfortable sharing mutually relevant information with one another. Of particular concern in situations where relevant clinical information is not freely shared between intimate partners is the effect this may have on informed consent. The clinician’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 as the clinician may be limited in his or her ability to explain why a given treatment is not offered, another treatment is recommended, or the recommended treatment is not optimal. Particularly when lack of disclosure between intimate partners limits the ability to obtain fully informed consent from all of the stakeholders, free information sharing should be strongly encouraged. Clinicians must decline to provide treatment when fully informed consent for the proposed treatment itself cannot be given by both partners because one partner would be subjected to risks that cannot be disclosed without violating the confidentiality of the withholding partner.

Disclosure can be complicated by the effect of learning the new information on the willingness of the patient to pursue shared reproduction. In some cases, there may be consequences of disclosure for the safety or well-being of the intimate partner. This is particularly so for women who may face violence, abuse, or rejection. As such, disclosure requires great sensitivity and must be accomplished in the manner most preferred by the patient while ensuring that it does not cause the patient harm.

When possible, providers should seek to deliver care modalities that avoid the risks concealed by nondisclosure. An example is the refusal by a male partner to disclose his HIV status. In such cases, the use of anonymous sperm donation, with the consent of the female partner, avoids any risk associated with the use of the male partner’s sperm. However, if the partner insists on use of his sperm, the clinician should decline treatment if the male does not disclose his HIV status to his female partner and thus any risk associated with the use of his sperm; the clinician has a responsibility to protect the female partner’s current and future choices about the risks she is willing to take for her health (1). Also and importantly, in the case of infectious disease, clinicians should be familiar with and abide by state and federal reporting requirements and should make these obligations clear to their patients.

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.

NONDISCLOSURE OF RISKS OF PHYSICAL HARM TO THE INTIMATE PARTNER

If the male partner carries an infectious disease, there can be physical harm to the partner from infertility treatment using the partner’s sperm. While strategies exist to significantly lower—and perhaps almost eliminate—transmission of HIV, no strategy can guarantee that disease transmission will not occur (2). 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 treatment and consideration of alternative treatment modalities can prevent transmission to both sexual partners and offspring.
In a previous Ethics Committee opinion (1), ASRM 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 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.” The Committee concluded that full disclosure of the gamete donor’s HIV status to a gestational carrier should be part of the informed consent process because of the potential, albeit small, risks to her. In cases in which HIV-infected intended parents are not gamete donors, however, the information is not relevant to medical management, although it might be of interest to the gestational carrier. The Committee reasoned that disclosure of such non medical information might interfere with the intended parents’ privacy rights and recommended that clinics communicate their policies about such disclosures with the parties in advance.

The Committee’s judgment that it was permissible to provide fertility care to HIV-infected gamete providers presumed full disclosure of the risks as part of the informed consent process. If the gamete provider’s HIV status is not disclosed, however, providing infertility treatment without informing the partner of the risk of HIV would subject her to risks of which she is unaware. By contrast, cases in which donor gametes are used, or in which the female but not the male partner is HIV-infected or otherwise infectious and artificial insemination is used, are cases in which treatment does 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 risks of transmission to the offspring (1). Clinicians may refuse care in this situation as the non-gestational parent would not be aware that treatment leading to pregnancy places the offspring at risk for acquiring an infectious disease.

**NONDISCLOSURE OF FACTORS THAT MIGHT ENABLE THE COUPLE TO AVOID THE NEED FOR INFERTILITY TREATMENT**

There are also cases in which one partner does not want to disclose information that could have enabled the couple to avoid the need for some or all infertility treatment. One example is a situation in which the male partner uses anabolic steroids or testosterone, leading to low or absent sperm count. In these cases, the female partner may undergo treatment with either intrauterine insemination or IVF. These treatments might have been avoided had the male partner discontinued his steroid use.

Other scenarios could include a male who is sterile due to a previous vasectomy or a woman who cannot conceive because of a 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 encouraged strongly 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 woman would be aware of the risks and benefits of fertility treatment. While ideally the information should be shared, clinicians may choose to offer fertility services when faced with such circumstances. 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 woman may not have disclosed to her partner previous sexual abuse leading to vaginismus and inability to consummate. Perhaps psychological treatment could help her achieve normal sexual function and avoid the need for insemination or IVF. However, the partner in such a case is aware of the existence of the vaginismus and the need for fertility treatment. Both partners can provide informed consent regarding the proposed treatment modality without breaking the confidentiality of the woman who prefers not to disclose the etiology of her inability to have intercourse.

**NONDISCLOSURE OF RISKS OF HARM TO THE OFFSPRING**

Harm to the offspring can occur when one or both partners may be aware of genetic risks that they do not wish to share. For example, a woman may know she is a carrier of an X-linked disorder such as fragile X. She may not wish to disclose the fact that their 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 BRCA, conferring risk on the children without the knowledge of the other partner. The male partner might have made different decisions in order to avoid these risks to offspring (using donor egg(s) and/or preimplantation genetic testing [PGT]) but is not given this information and therefore could be faced with a situation that he would have chosen to avoid if full disclosure had been made. If the woman is the one affected, and she chooses to undergo PGT or oocyte donation, the risks are potentially avoidable without disclosing her carrier status to her partner. Similarly, if the male is a carrier and PGT is undertaken, the risks could be avoided. In such situations, however, fully informed consent for the need both for in vitro fertilization (IVF) and PGT could not be obtained without revealing the carrier status of the affected partner, and disclosure should be strongly encouraged.

Another situation is the potential for transmission of an infectious disease to the offspring. Recently, Zika virus has been shown to be sexually transmitted via sperm (3–5). At the present time, Zika virus testing of semen following potential exposure is not available. Given the risks of transmission to the female partner and the potential risk of birth defects to the offspring, males with possible Zika exposure should be strongly encouraged to disclose this information to their female partners. Similarly, if the female is infected with HIV, hepatitis B or hepatitis C, there are risks of transmission to the offspring that the male partner might prefer to avoid.
NONDISCLOSURE OF PARTNER’S HEALTH STATUS

In some cases, one or both partners may have health conditions that they have not disclosed to the other. These might include prior treatment for cancer or for other conditions that have played a role in the need for infertility care. Here, the primary risk is that one partner may undergo the fertility care without knowing that s/he has a greater than average risk of being left to raise a child on his or her own. In a prior 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” [6]. This discussion assumed that both partners were aware of the possibility of one 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 he or she would prefer to avoid.

There are also situations in which pregnancy is risky to the patient due to 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 her carrying a pregnancy is associated with a risk of aortic dissection and death. Knowing this, he may have opted out of participating in 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 due to maternal death. Certainly, such situations also increase the risk for pregnancy and neonatal complications, including preterm birth. Disclosure between intimate partners should be encouraged strongly in these cases.

EMOTIONAL HARM TO THE RELATIONSHIP

There are situations in which the partner who does not want to disclose information fears that disclosure would harm the relationship. For example, a person with androgen insensitivity syndrome (AIS) who presents socially as a woman will not have ovaries or a uterus. She may not wish to disclose her genetic identity to her partner. The patient and physician understand the etiology of the infertility and the reason why pregnancy cannot be undertaken, but the partner is not told. Knowing may change the partner’s view of the female with AIS and may cause a deterioration or disintegration of the relationship. In such cases, the affected female’s confidentiality cannot be breached, but this sets up a difficult situation when trying to explain the causes of infertility to the partner as honestly as possible and to answer any resulting questions.

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, again causing harm to the relationship.

Yet another scenario is a case in which the male partner has 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 spontaneously by the male partner will likely become apparent. Absent 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 the child may suffer 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 to 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 to others, the patient should be counseled about the advisability of disclosure. A related recommendation is that if confidentiality cannot be kept (for example, 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 might be harmful to the patient if it results in loss of important benefits, damage to relationships, or even violence. Confidentiality becomes especially problematic, however, when it is associated with risks to others [7–10].

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

- The partner might face physical risks due to the potential of disease transmission or the need to undergo procedures that he or she might choose to avoid.
- The partner might face risks to offspring that he or she might choose to avoid.
- The partner might 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 might encounter economic costs that could possibly be avoided with disclosure.
• The partner might remain ignorant of 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.

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

If one 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 might allow infertility treatment to be avoided, informed consent to infertility treatment is possible, but informed consent regarding the range of options is not. Because there is a possibility that the treatment might be avoided, however, 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 him- or herself. However, the nondisclosing partner has very strong interests in knowing about risks to offspring and participating in decisions about whether to pursue other options. One example of such a situation is a woman who carries fragile X (an X-linked dominant pattern disorder that causes a range of developmental problems including learning disabilities and cognitive impairment) and wishes to use PGT to avoid transmission of this disease to her offspring. Her male partner may wish to avoid the cost of IVF and PGT, to consider options such as donor gametes, or to proceed with unassisted reproduction and accept the risk of having an affected child. He might not be aware of the full range of options without disclosure by the physician or his partner of the rationale for PGT. The reasons for PGT as well as the specific testing that will be performed should be disclosed to both parties as part of the informed consent process. Clinicians may ethically refuse to provide treatment in situations where informed consent for PGT cannot be obtained [11].

In cases in which a patient is at increased risk of negative health effects or pregnancy-related risks resulting from fertility treatment, she is taking personal risks that may result in her partner being left to raise children on his own. While there are cases in which such risks are higher than average due to specific medical determinants, such risks are ones that anyone might 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 [12]. 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 [13], 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 might 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 might regard as material to the relationship, such as the effects of a prior abortion, the reasons for nondisclosure are likely very 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 must keep the confidence.

**SUMMARY**

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 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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REFERENCES


