Mandatory counseling for gamete donation recipients: ethical dilemmas

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Mental health professionals have engaged in mandatory pretreatment counseling and assessment of patients seeking treatment at IVF programs in the United States since the 1980s. At present, most recipient patients undergoing IVF with egg or embryo donation in the United States are required to meet with a mental health professional for one pretreatment session. Mandatory counseling of gamete recipients is fraught with ethical questions for the mental health professional. Attention to issues of autonomy, confidentiality, role clarity, along with self-evaluation and openness with the patient can help lessen the impact of these ethical challenges. (Fertil Steril® 2015;104:507–12. ©2015 by American Society for Reproductive Medicine.)

Key Words: Counseling, ethics, mental health professional, gamete donation recipients

This article examines first how mandatory or required counseling for gamete recipient patients raises several ethical concerns, including implications for patient autonomy, informed consent, confidentiality, nonmaleficiance, and fairness. Second, it explores how mandatory counseling raises questions about autonomy for mental health professionals, with a final look at how mental health professionals can identify, address, and resolve ethical conflicts.

The value of counseling and psychological support in fertility care has been recognized for some time. A large body of psychological research has confirmed that infertility is stressful, constitutes multiple losses, and evokes a wide range of emotional responses that include sadness, depression, anxiety, grief, and isolation. Furthermore, the experience of assisted reproductive technology (ART) can add to the psychological strain. Research has also shown that psychological counseling for patients with infertility can provide effective assistance, reduce levels of anxiety and depression, increase coping, and improve the quality of life.

Less recognized is that mental health professionals have engaged in mandatory pretreatment counseling and assessment of patients in IVF programs in the United States for more than two decades. One of the first articles describing a role for the mental health professional in an IVF program appeared in 1984 (1). The use of mandatory counseling arose in part out of the uncertainties associated with starting the first IVF programs in the United States and the unknown psychological effects of IVF treatment. The mental health professional could then serve as a safety mechanism or gatekeeper to screen out possibly unstable patients (2). Although professional guidelines at that time did not address counseling for patients undergoing donor insemination (DI), mandatory pretreatment counseling for donor sperm recipients was instituted in several, primarily academically based, ART programs in the early 1990s (3, 4). Over time with the expansion of IVF and reassurance that patients with infertility presented no more evidence of psychopathology than any other group, most ART programs moved away from mandatory pre-IVF counseling.

Since its introduction >25 years ago, IVF with oocyte donation has become highly successful. But its introduction into ART programs has been accompanied by questions about its social, legal, and ethical acceptability. Thus, as with the introduction of IVF in the 1980s, the advent of oocyte donation prompted concerns about psychosocial screening and counseling of patients seeking oocyte donation. The involvement of mental health professionals in mandatory counseling has grown with both the increase in ART

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cycles using donated gametes and with professional recommendations that "patients may benefit from psychological counseling" (5).

Counseling, screening, and educating patients about the implications of gamete donation has become a central recommendation for pretreatment counseling in guidelines issued in the United States, United Kingdom, Australia, New Zealand, and Germany, among other countries. Internationally, there remains considerable variation in recipient counseling, ranging from legislated, recommended, or minimal (6). Currently, most recipient patients in the United States who undergo IVF with egg or embryo donation are required to meet with a mental health professional for one session pretreatment. Both the psychological literature and professional guidelines describe multiple goals for the mental health professional who counsels gamete donation recipients. These include education, counseling, and assessment/evaluation (7). Thus, since the first ART programs, mental health professionals have been positioned as potential or actual gatekeepers.

ETHICAL CONSIDERATIONS

Although there is general agreement about the importance of counseling for recipients, the decision whether to require it has been left to individual programs in the United States without a profession-wide debate about the ethical implications.

Patient Autonomy and Harm to the Patient

Mandatory counseling can take away the recipient's self-determination or autonomy in choosing whether to engage in pretreatment counseling and has the potential to add harm. For some patients, counseling becomes an obstacle to overcome to receive treatment, requiring them to take more time off work, drive a distance, and pay additional costs. In addition, patients often feel that they do not need to talk to a mental health professional. Perhaps surprisingly, many patients with infertility have never engaged in counseling before. Associating counseling with the stigma of mental illness, they are often nervous and resentful for being singled out just for needing ART to become parents. For some, it is culturally foreign and embarrassing to discuss personal feelings with a stranger. Although patients report diverse opinions about mandatory recipient counseling, the criticisms typically reflect concerns about cost, loss of choice, and paternalism (8).

Values and Utility

Despite the potential negative impacts, there are arguments in favor of mandatory counseling based on the notion of utility: an action that benefits the patient. The strongest evidence in support of required pretreatment counseling comes from research about patient attitudes. There is evidence that patients who participate in required counseling before an IVF cycle find it helpful and feel positive about the counseling. Hammarberg et al. (9) found that most women who attended mandatory pre-IVF counseling thought that it should be part of the treatment. Hakim et al. (10) surveyed 69 couples undergoing treatment who were required to attend a psychosocial counseling session before treatment. The majority anticipated the session would be beneficial. After the session, views were significantly more positive. The majority (>95%) found the session to be helpful and informative. A Swiss study (11) reported that when a routine pre-IVF counseling session was expected (although not required), most patients followed through with counseling. Of those who had not planned on attending, 86% found it helpful. Among those who had already wanted to attend a session, 95% found it helpful. The researchers also found that when all patients were expected to see a counselor, it was normalized and more acceptable than if counseling was required only for some patients (11). The study by Daniluk and Leader (12) of 43 infertile couples found that most men and women believed there was a need for psychological services.

There is additional research on how gamete recipients view the requirement to attend a counseling session. A 1994 study of couples planning treatment with DI found that the majority believed psychological counseling should be mandatory (13). An Australian study (14) found that when gamete recipient patients were required to attend a counseling session, they typically found it beneficial and subsequently had a positive attitude about the experience. A U.K, researcher found that some patients wished the counseling was required (15). U.S. research indicates that gamete donation recipients typically express the need for support and wish for assistance, especially in discussing disclosure. Shehab et al. (16) found that most couples recognized the potential value of counseling; some had not recognized a need for counseling during treatment but in retrospect wished they had received it. Hershberger et al. (17) found that women using oocyte donation found counseling helpful.

Despite widespread agreement among professionals and patients that infertility counseling is beneficial, the uptake rate when offered but not required, can be very low (18). There are many reasons, including cost, time constraints, stigma, uncertainty about what counseling involves, protection of privacy, and fear of what the counselor might think. Another factor that influences uptake is how the recommendation or referral is made. Patients are more likely to follow through if the recommendation is made personally by their physician, and when the benefits of counseling are explained. The research then suggests that if not required to attend a counseling session, many patients will not do so, although those attending find it helpful (10, 18, 19).

Although mandatory counseling impacts patient autonomy and intrudes on confidentiality, there is reason to believe that counseling can be beneficial. Arguably, the paternalism implicit in mandated counseling is limited in scope and serves ultimately to maximize the patient's autonomy and decision-making about family building with donated gametes.

Egg Donation Recipients versus Sperm Donation Recipients

The notion of justice requires us to give equal consideration to and provide equal opportunities for counseling.