Insufficient fertility counseling and decisional regret: a call to raise our standards for fertility preservation counseling prior to gender-affirming care

With increasing insurance coverage, societal visibility, and acceptance of gender-affirming treatments, more transgender and non-binary (TGNB) individuals are seeking care. As population surveys show rising numbers of high school age individuals identifying as TGNB, more people will be receiving gender-affirming care before considering or completing family building. Health care providers, including fertility specialists, need to be able to counsel these patients accurately and sensitively about the possible reproductive consequences and the available options for fertility preservation. The study published in this issue by Vyas et al. (1) describes the results of electronic surveys sent to a large cohort of patients of a gender health program at a large university hospital, examining reproductive intentions and decisional regret, as well as the barriers to pursuing fertility preservation.

In reading this study, we were struck by the many parallels between fertility preservation for TGNB individuals and fertility preservation in the setting of a cancer diagnosis. Previous research in the field of oncofertility has established that the potential for infertility after cancer treatments can be as painful as the cancer diagnosis itself, with fertility preservation counseling instrumental to coping for some individuals. A cross-sectional study of 747 female adolescent and young adult cancer survivors, at a mean of 7.7 years after their cancer diagnosis, found moderate to high reproductive concerns in 44% of respondents. While prior chemotherapy and radiation treatment were associated with increased reproductive concerns, many cancer survivors desired fertility counseling regardless of their cancer type and infertility risk (2). Although an individual's risk of infertility is highly dependent on their age, cancer pathology, and treatments received, fertility preservation counseling has become the standard of care at the time of cancer diagnosis for youth and reproductive age individuals. A recent investigation of parenting desires among over 400 female adolescent and young adult cancer survivors found that 22% were voluntarily childless (3). Despite known variations in reproductive intent, guidelines have been established to encourage discussions of fertility throughout the cancer and survivorship care of young people with a cancer diagnosis and quality measures have been created to encourage cancer centers to meet this standard of care. In a manner similar to cancer treatment, gender-affirming surgeries and hormone treatment can be life-saving and also represent a threat to an individual's reproductive potential. Although fertility preservation counseling is recommended in both settings, a key distinction between these populations is the lack of quality measures and established standards to promote fertility preservation counseling for TGNB individuals.

Many TGNB individuals pursue gender-affirming care during their reproductive years, as supported by the investigation by Vyas et al. (1) with a mean age of 29 years at the time of intake, and express interest in parenting biologically-related children in the future. In the setting of the definitive impact of gender-affirming surgery and the potential deleterious effects of gender-affirming hormone care on an individual's future reproductive potential, there is consensus among major medical societies, including the American Society for Reproductive Medicine, World Professional Association for Transgender Health, Endocrine Society, and European Society of Human Reproduction and Embryology, that fertility preservation counseling should be offered to TGNB individuals before initiation of gender-affirming treatments. Despite this consensus in recommendation, Vyas et al. (1) demonstrated that fertility preservation counseling is provided inconsistently with 26% of respondents reporting that health care providers had not discussed family planning. When provided, such counseling was likely often incomplete with 49% of respondents receiving counseling from their primary care provider, 20% from a medical endocrinologist, and only 1% from a reproductive endocrinologist (1). A previously published survey of over 200 transgender healthcare providers in 12 countries found variability in knowledge relating to fertility preservation, including the impact of gender-affirming therapies on fertility and whether certain fertility preservation options were established or experimental. Despite this variability in knowledge among providers, less than half of the respondents endorsed routinely referring transgender patients to fertility specialists (4).

These findings demonstrate a failure to meet the standard of care for TGNB individuals, which likely contributes to the low uptake of fertility preservation services among this population. Fertility preservation for TGNB individuals as well as the impact of gender-affirming hormones on an individual's reproductive capacity is a rapidly evolving field and it may not be reasonable to expect primary care providers and medical endocrinologists to remain up to date on the research. The lack of standardized guidelines for fertility preservation in the setting of gender-affirming hormone treatments with nuances, such as the timeline required (if any) for discontinuation of hormones, use of random start protocols to decrease time off or delay in initiation of gender-affirming care, and use of an aromatase inhibitor to limit the physiologic rise in estradiol during ovarian stimulation, create a challenge for primary care providers and general obstetrician-gynecologists to provide adequate fertility preservation counseling for this population. Given their specialized training, reproductive endocrinologists are uniquely equipped to discuss fertility preservation procedures and measures that can be used to mitigate gender dysphoria allowing for more complete reproductive counseling for TGNB individuals, which may lead to increased use of fertility preservation services.

A lack of consistent and effective fertility preservation counseling characterizes only one of many barriers to fertility preservation services for TGNB individuals. TGNB people

represent an underserved population in medicine in the United States, with high rates of poverty, suicide, and violence on the basis of gender identity. Financial restrictions are a primary limiting factor as demonstrated by Vyas et al. (1), with 36% of respondents identifying the cost of treatment or lack of insurance coverage as a barrier to fertility preservation. TGNB individuals often are excluded from non-profit and charitable institutions that may help to offset this financial burden for individuals with cancer seeking fertility preservation. Advocacy for increased insurance coverage for fertility treatments often focuses on cancer survivors in the context of established standard of care for fertility preservation in these patients, with limited discussion or inclusion of TGNB individuals (5). In the United States, there already is significant heterogeneity in state-specific legislation relating to insurance coverage for fertility services. In the minority of states that do have mandates for insurance coverage of infertility, patients often must meet cis-normative definitions of infertility and it is not clear whether "medically necessary" treatments that impact fertility include gender-affirming care (5).

The lack of adequate fertility preservation counseling and the demonstration of moderate to severe decisional regret in this large cross-sectional cohort should act as a call to action to create guidelines and quality measures to improve access to high-quality fertility preservation services for TGNB individuals. For example, the Centers for Medicare and Medicaid Services assesses for fertility preservation counseling before chemotherapy in their hospital inspections and in making Cancer Center designations, and the US News and World Report awards points for fertility preservation in their hospital rankings, but to our knowledge, neither consider fertility preservation counseling before gender-affirming care as part of their criteria. Health care providers should advocate for increased research, access, and insurance coverage to expand fertility preservation counseling and options for TGNB individuals, so that we can provide this traditionally marginalized population with the fertility care they deserve.

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