

# Virtual Mentor

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## ETHICS CASE

### Informing Patients about Declining Fertility

Commentary by Marc M. Beuttler, MA, Kara N. Goldman, MD, and Jamie A. Grifo, MD, PhD

Niki, a 37-year-old single woman, has been seeing her gynecologist, Dr. Goldstein, for the past 15 years. A busy attorney trying to make partner at a high-powered firm, Niki has focused on her career during that time. She wants to marry and have a family, but is surrounded by women who have waited until their late 30s and early 40s to have children and envisions doing the same. From what Niki sees around her, this timeframe has become the norm for professional women. When she calls to schedule her annual visit, the receptionist tells her that Dr. Goldstein is on an extended leave, but that one of her partners, Dr. Chang, can see Niki instead.

Everything proceeds as usual during the visit. When Dr. Chang asks whether Niki plans on having children, she says that she plans on having at least one child. Dr. Chang explains briefly that a woman's fertility naturally begins declining in the mid-30s, and she offers Niki a serum anti-Mullerian hormone (AMH) test to evaluate her ovarian reserve [1]. She suggests that Niki might find this information useful in deciding how to balance her career and reproductive future. As a lifelong planner, Niki agrees to the test and thanks Dr. Chang for telling her about it. As she is leaving, Dr. Chang tells her that Dr. Goldstein is reviewing her patients' test results remotely and will be the one to call her with them.

A week later, Dr. Chang is just coming out of another patient visit when her assistant tells her that Dr. Goldstein is on the phone, waiting to speak to her about "a very urgent issue." When she picks up the call, Dr. Goldstein says in a very agitated manner, "Why would you check AMH levels on Niki? They came back nearly undetectable. What am I supposed to tell her? She doesn't even have a partner! She's going to freak out, and all of this could have been prevented!"

Dr. Chang replies that she provides fertility counseling and AMH testing to all her patients because she believes patients deserve access to this information. Dr. Goldstein counters that this approach creates unnecessary fear among career women who should not face additional pressure from their physicians to think about children when they can use reproductive technologies to achieve pregnancy on their own timeline.

### Commentary

Niki sees female colleagues having children into their late 30s and early 40s, and today the media often highlights celebrities conceiving into their mid-40s. The

message to women is deceiving; a woman is unlikely to conceive in her 40s without assisted reproductive technologies (ART) and possibly even donor oocytes [2]. Surveyed women often overestimate the likelihood of spontaneous pregnancy at all ages [3]. Operating on the knowledge that fertility declines gradually but significantly beginning at age 32, and more rapidly after age 37 [2], Dr. Chang educates Niki on declining fertility and recommends anti-Mullerian hormone (AMH) testing.

Trends clearly reflect that women are delaying childbearing: over the last three decades there has been a 150 percent increase in the number of women in industrialized countries giving birth between the ages of 35 and 39 and a significant increase in the number of women aged 40-44 who do so [4]. Increased access to ART affords women the opportunity to attempt to defer reproduction, but it doesn't guarantee biological parenthood. The percent of autologous in vitro fertilization (IVF) cycles resulting in live birth is approximately 22.1 in women ages 38-40, 12.4 in women ages 41-42, and only 5 in women ages 43-44 [2].

At the same time, the miscarriage rate increases to approximately 20 percent in women ages 38-40 and 30 percent in women ages 40-42 [5], and the number of chromosomally normal embryos in a patient's cohort diminishes significantly with age [6]. IVF with preimplantation genetic screening (PGS) followed by embryo transfer can overcome the diminishing effect of maternal age on implantation after IVF [7, 8]; however, this requires that a patient undergo IVF with PGS and assumes that a woman will have a normal embryo available for transfer, which is true for less than half of women over 40 years of age [6]. Therefore, the most reliable way to ensure that a woman not only conceives but also has a safe pregnancy and healthy baby is for her to conceive at a younger age, or at least with younger oocytes.

### **Informed Decision Making**

Reproductive physicians have a responsibility to educate and to counsel those patients who express an interest in becoming pregnant, and, while testing AMH levels may not fall within a typical gynecology visit, Niki's age and interest in having children make testing her ovarian reserve relevant. However, it is not enough to merely recommend testing; the rationale behind and accuracy of such tests should be explained to the patient and the physician should use this opportunity to help the patient reflect on what she will do if she receives surprising results. These difficult conversations encourage the patient to take ownership of decisions related to testing and her future.

If Niki's aim is to achieve a biological pregnancy, and especially if she wishes to have more than one biological child, it is in her best interest to have access to this knowledge and the tools with which to make an informed decision. In addition to testing AMH levels, Dr. Chang could also have suggested other methods of ovarian reserve testing, including early-follicular-phase follicle stimulating hormone (FSH) and antral follicle count [1]. While these tests have limitations, taken together they may help the patient and physician to interpret results. Conflicting information

would highlight the fact that such tests do not predict the future and may sometimes overstate certain data. Relying on one abnormal lab result might force Niki to make drastic decisions regarding her reproductive future. Providing her with supplementary information could help to eliminate or qualify potential risks and paint a fuller picture from which to decide what procedures best fit Niki's life goals.

With knowledge of a declining ovarian reserve, Niki might consider attempting to conceive in the immediate future using anonymous or directed donor sperm, or she might choose cryopreservation of her oocytes for later use [9]. Oocyte cryopreservation is widely offered as a means to preserve fertility for women at risk of fertility loss because of cancer treatment or another illness. Women are also beginning to pursue oocyte cryopreservation electively as a means to defer reproduction for personal or professional reasons [9, 10]. The technology has evolved to the point that live birth rates using cryopreserved oocytes are similar to live birth rates using fresh oocytes [11]. If Niki is unable to pursue pregnancy at this point in her life, cryopreserved oocytes could offer hope for biological parenthood in the future when her only other alternative might be donor gametes [12]. Surveyed women who pursued oocyte cryopreservation for deferred reproduction described the process as “empowering” and reported feeling that they had improved their reproductive futures [13]. Whatever Niki decides, her ability to make an informed decision is impossible without professional knowledge on declining fertility.

### **Autonomy and Paternalism**

By providing information, Dr. Chang seeks to respect Niki's reproductive autonomy; that is, her right to determine her own actions regarding family planning [14]. Respect for autonomy extends from the idea that no one is in a better position to know how a patient's life should go than the patient herself [14]. Thus Niki is the best one to determine what to do with Dr. Chang's professional knowledge in the context of her life goals. Autonomous choices should be informed by professional knowledge and relevant information without a physician's preconceived opinions or value judgments. Deciding what is relevant is not always easy; one does not want to unduly influence or burden a patient with knowledge of inconsequential theoretical risks. Ultimately, the physician must use medical expertise and judgment in providing a patient with the information that is relevant to his or her goals [14].

Here, Dr. Chang has decided that information about Niki's current and future state of fertility may serve her interest in having a child or children. Dr. Chang offers this information in support of Niki's values and goals. If Niki wishes to have biological children, information regarding her ovarian reserve could help her achieve the family architecture she desires and could impact her immediate life as well as her overarching life goals and values. Though it is not a physician's duty to presume what is in a patient's best interests, if a physician recommends testing to determine a given risk, it is his or her responsibility to initiate conversations on how to use and evaluate test results and to be sure that a patient understands testing options. Failure to educate patients could affect decision making and diminish autonomy.

While Dr. Goldstein is perhaps correct that knowledge of AMH levels will force Niki to weigh her options and to consider both her career and family goals, it is overly paternalistic for Dr. Goldstein to use deception, nondisclosure, or manipulation to bypass Niki's preferences and to guide or force her actions, even with the justification that doing so is in her best interests [14]. Sometimes we feel that paternalism is justified, e.g., in the case of seatbelt laws or compulsory education. But in the case of the patient-physician relationship, it is better to err on the side of respect for patient autonomy and empower patients in a nondirective way. With this in mind, physicians should offer what they believe is the best standard of care. If they believe that standard of care involves offering a particular test, in this case AMH, then the physician should clearly inform the patient about its existence, its use, and its accuracy. The physician is a consultant who helps facilitate the patient's own reasoned and reflective decisions about reproduction and health in the context of individual life goals and expressed preferences. Maintaining this role is an important means of respecting autonomy and eschewing paternalism.

Dr. Goldstein's anger at Dr. Chang may actually reflect regret that she herself did not consider Niki's ovarian reserve. Surely the patient's interest in having children has come up at least once during the 15 years that Dr. Goldstein was Niki's physician. Whatever the reason, the conflict between the two physicians' standards of care and opinions of what constitutes responsible practice highlights the ongoing tensions between paternalism and autonomy in medicine. While Dr. Goldstein is wrong to withhold testing that could provide Niki with valuable information, Dr. Chang's testing of Niki's AMH levels without discussing possible risk could have resulted in a subtler harm. The patient should be informed of the availability of testing and its limitations and ultimately be empowered to make a decision about whether or not to pursue it.

Medical practices vary, and while a physician seeing someone else's patient has a responsibility to keep the primary physician informed, he or she also has a duty to deliver what he or she believes is the best standard of care. In this regard, Dr. Chang acted correctly: she provided what she believed was the best standard of care; she sought to respect Niki's autonomy by providing her with relevant professional knowledge; and she sent notes and results to Dr. Goldstein, the primary physician.

Dr. Goldstein's worries are valid, but this does not permit her to withhold relevant information about Niki's ovarian reserve. Rather, she should sensitively inform Niki about her ovarian reserve, what this means, and what her options are. Discussing the risk of diminishing fertility is difficult, but fully informing a patient of her options so that she can make the best decision for herself within the context of her own life is what respect for persons requires.

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