

## The Truths that Make Us Free: Ethical Reflections on Reproductive Endocrinology

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**THE TRUTHS THAT MAKE US FREE:**  
**ETHICAL REFLECTIONS ON REPRODUCTIVE ENDOCRINOLOGY**

**INTRODUCTION**

Reproductive endocrinologists make the seemingly impossible possible, a miraculous event in the lives of countless couples who want nothing more than to welcome a biological child – and perhaps many more – into the world. Their expertise is “the gift of life” – no pressure or anything). As Dr. G. put it, “we try to find a way to give each patient we encounter everything we have, and that means doing whatever it takes to make her dream of being a parent come true.”

While the enterprise of reproductive endocrinology is rather brightly lit and respected, bordering on biological wizardry, it encounters as many bioethical speed-bumps as biological triumphs. According to the five reproductive endocrinologists I encountered on rounds, they struggle most with the concept of “false hope”: the idea that patients will inevitably believe their skills and methods to be foolproof and faultless, that there is a perfect chance of success in practice, that they will become pregnant without hindrance, without the chance of failure. But this is not so. According to Dr. G., “several of these endeavors fail, and they are incredible expensive; so we leave individuals not merely without hope, but without a significant portion of cash as well.” Among other concerns surrounding this issue is the hesitance of the clinicians to be forthcoming with potentially poor news regarding the success of a particular fertility treatment. Another member of the team, Dr. W., framed it this way: “When I begin to recognize some inconsistencies in the data, which therefore suggests the possibility – but *just* the possibility – of failure, I’m really not sure if I’m morally obliged to share this with the patient. I risk two things: first, being wrong; second, shattering her hope while still being wrong. I guess I could look at it as preparing her, but I’m not even positive myself of what I would be preparing her for.”

**SOLVING THE “THERAPEUTIC PRIVILEGE” DILEMMA**

Among other things, Dr. W.’s concern turned on the notion of “therapeutic privilege,” a rather controversial exception to obtaining informed consent from a patient with decision-making capacity. The idea is that giving individuals the truth about their unfortunate or, in this case, potentially unfortunate, diagnoses and expecting them to make an agonizing choice to give or withhold consent for burdensome (be it physical, emotional, or otherwise) treatment with an uncertain outcome might devastate them.

Unfortunately, when patients are never told unfortunate and even potentially unfortunate diagnoses, an intolerable situation often develops. Treatments are given, and clinicians and friends have to perform a dance of pretending – pretending that the dilemma is only temporary, pretending that the situation, and the persons most directly involved, “will soon be fine.” Although it may seem that this is the merciful thing to do, most often it is not. There is no evidence that informing patients of their situation when the diagnosis and prognosis are not good – again, even if only potentially so – is more dangerous than pretending everything is fine.

A nuanced notion of informed consent can rectify pressing problem above. In the movement from fastened rules to honored values, the concept of shared decision sets forth the two major elements of the informed consent doctrine: information and consent. The primary task is for clinicians to inform patients about all of the medically accepted treatment options, as well as the risks, burdens, and benefits associated with each. In receiving this information, patients are able to exercise properly the appropriate freedom necessary for consent, in order that they might participate meaningfully and morally in their treatment. There is a temptation for clinicians to neglect disclosing all of the burdens, especially those that are only potential, because they are naturally reluctant to discuss comprehensively the possible side effects of interventions they feel the patient needs or even genuinely desires – here, becoming pregnant and delivering a healthy child. Yet the patient needs this information if her consent is going to be truly informed. The requirement that clinicians disclose all potential medical complications also means that the clinicians may have to provide information that is less than preferable.

Among reasonable approaches to dilemmas such mentioned above is to ask the patient what she wants to know *before* the process begins. This means that the clinician will ask the patient – and in this way give *her* control over – whether she would like to be informed if indicators become present that might, however minutely, connote the existence of a potential future complication. This certainly makes easier the difficult and heavy judgment call the clinician would, at best, struggle to morally defend in the absence of such a conversation. Further, the more the patient consensually controls what she knows, the less there exists a moral dilemma. To be sure, this alone does not relieve the burden of caring for those who may very likely become disappointed, but it very unlikely affects any ethical justification for freely-chosen, reasonable, realistic, and responsible actions.

### **MORAL OF THE STORY**

The great temptation of modern medicine, not always resisted, is to move beyond the promotion and preservation of health into the boundless realm of human happiness and well-being. The root problem of “biological hope” and potential disappointment is both medical and philosophical or religious. “Why is this treatment not proving effective?” can be asked as a technical, biological question, or as a question about the meaning of life. When medicine tries to respond to the latter, which it is always under pressure to do, it moves beyond its proper role. It is not medicine’s place to lift from us the burden of that suffering that turns on the meaning we assign to the biological effectiveness of medical treatments for the body. It is not medicine’s place to determine when the burden of disappointment, whether actual or potential, is too great to be borne. Medicine should try to relieve human suffering, but only that suffering that is brought on by *biological* phenomena, not that suffering that comes from anguish or despair at the human condition.

Clinicians ought to relieve those forms of suffering that medically accompany serious biological risks (physiological, psychological, or otherwise), even if only potential. They should relieve pain (in a broad sense), do what they can to allay anxiety and uncertainty, and be a comforting presence. As sensitive human beings, clinicians should be prepared to respond to patients who ask why things are simply not working out for them, or why it was not “meant to be” for them to become pregnant. But here the clinician and the patient are at the same level. The

clinician may have no better an answer to these questions than anyone else, and certainly no special insight from his or her training as a clinician. It would be terrible for clinicians to forget this, and to think that medicine, in providing wishful words or, in contrast, not providing potentially disappointing but genuinely concerning medical data, with no foundation in authentic biological hope, has found its answer to the riddle of life. It would be a false answer, given by the wrong people. It would be no less a false answer for patients. The problem is precisely that, too often in human history, ignoring the real potential for disappointment and its subsequent effect of producing ever greater vulnerability has seemed the quick, efficient way to put aside that which burdens us. It rarely helps, and too often simply adds to one wrong still another.