

Editorial

An evolving landscape: reproductive genetics, new technologies and health care over the next decade

The rapid advancement of reproductive science, fueled by such major events as the completion of the human genome project in April 2003 [1] and marked by technologies such as preimplantation genetic diagnosis (PGD), has brought a sea of change in health care that has already begun to impact our lives. And, for all of the benefits and risks involved, reproductive genetics will continue to influence health care in significant ways over the next decade. The swift growth in these new technologies calls for reproductive health providers to thoroughly educate themselves, to better understand implications for health care practice, to advocate for clear safety measures to ensure the health and well-being of those who use these technologies and to advance policies that promote health equity.

Advancements in genetics generally, and in reproductive genetics specifically, bring with them a host of ethical, legal and social concerns that the reproductive health care community will face for years to come.

As a result, we are facing three major changes:

- (1) *From macro to micro: Changing treatment approaches.* For general medicine, the historical process of patient treatment will change from current methodologies to more focused, symptoms-based treatment and prevention [2]. At the same time, an increased focus on genetics as the basis of disease could lead to an unfortunate unintended outcome: due to distraction, far less attention may be paid to social and environmental factors that cause or contribute to medical conditions [3]. The implications for the field of assisted reproductive technologies (ART) are likely to be changes in focus from a general desire for healthy outcomes to addressing ethical concerns, such as sex selection and the increase in screening for specific genetic problems.
- (2) *Pharmacogenetics.* New genetics research gives us the potential to better understand how people process medications, chemicals, hormones and other agents, which raises the possibility of more targeted treatment strategies that involve customized medicines, alternative therapies and healthier

lifestyles. Personalized treatments raise concern, however, about higher costs and lack of access to those who cannot afford them. The trend toward privatized medicine also places increased burden on individuals rather than fostering a system of health care promotion for all. And, finally, new research using race as a genetic category and the accompanying development of pharmaceuticals patented and marketed to race-specific groups [such as isosorbide dinitrate/hydralazine (trade name: BiDil), a Food and Drug Administration (FDA)-approved drug to treat heart failure specifically in African Americans] have the potential to revive biological theories of race [3]. These theories have long been discredited, including by the Human Genome Project itself, and would create false notions about the cause of health disparities [4].

- (3) *Brave new world or back to the basics?* Essentially, both. The intricacies we learn from genetics research and the nuanced reproductive health technologies that emerge will make basic, high-quality patient care and counseling more important than ever. With new technologies developing faster than the implementation of safety requirements, the need for research on the impact of these technologies on health and society is critical. Reproductive health professionals will need to assure that women retain control of their reproductive decision making by having as much evidence-based information as possible.

With all these new developments, two of our core principles as reproductive health professionals will still remain fundamentally the same over the next decade: excellent patient care and counseling are essential, and reproductive health advocacy is the key to healthy reproductive lives.

Patient care and counseling: As individuals and couples face decisions about whether to use genetic testing and ART, practitioners will be ever more challenged to provide comprehensive and unbiased counseling for women who are pregnant or wishing to become pregnant. With the

availability of prenatal, prepregnancy and preconception testing of fetuses, embryos and gametes for hundreds — and potentially thousands — of genetic conditions, prospective parents will have to make decisions about whether or not to use available genetic testing and what to do when they receive positive test results. While prenatal testing has been used for decades and providers have long counseled their patients in this area, they have not often had access to full information about raising a child with a disability. Medical education programs will need to incorporate curricula that involve contact with children with disabilities and their families so that providers can more effectively counsel their patients about the reality of raising a child with a disability. At the very least, familiarity with appropriate referral and support programs will be necessary.

These technologies are helping countless people build their families. At the same time, it is important to remember that ART is an industry that has everything to gain when couples choose to use these technologies. Health care providers can be an important source of unbiased information and counseling for patients who are considering ART and need information about its risks, benefits and success rates in order to make an informed decision as possible.

Women and men struggling with infertility often undergo expensive and potentially unnecessary treatments, the long-term health effects of which are unknown. The increasing popularity of technologies like in vitro fertilization raises some concerns that women are not receiving enough information and counseling. Reproductive health care providers can — and should — provide much needed, unbiased information about the risks and benefits of the procedures and process involved. Patients need thorough information about the egg retrieval process, whether they are having eggs harvested for themselves or for the benefit of others [5]. They also need to know about the risk of multiple births and the unknowns about long-term health effects of hormone injections.

Patients need evidence-based information about whether medical intervention is likely to help them conceive a pregnancy. For example, recent research indicates that the live birth rate for those who continued to try to conceive naturally and those who opted for common first-line treatments such as clomiphene (Clomid) and unstimulated intrauterine insemination was the same. However, the women in the “trying naturally” category expressed the least amount of satisfaction with their course of action [6]. While patients struggling with infertility begin to educate themselves about the common medical interventions their peers are opting for, health care providers can help patients manage their expectations for success and help them understand when and if medical intervention is an appropriate next step.

Fertility clinics are also at liberty to define their success rates in very selective ways [7]. For instance, it is easier to achieve high pregnancy rates when you limit your clientele to those who have the best chances of conceiving and maintaining a pregnancy. Routine health care providers, who already have a preexisting relationship with patients, can help them gain a

realistic understanding of how successful fertility interventions may be in their specific cases.

There is currently very little coordinated care between most fertility clinics and other health care providers. Often, when fertility treatments have resulted in pregnancy, a woman is passed off to her obstetrician/gynecologist with little to any follow-up from the fertility clinic. Providers must do more in the future to ensure there is continuity of care and tracking of long-term results.

Advocacy: Although platforms and positions will become more complex than in the past, advocacy for reproductive health rights and justice will be more important than ever during the next decade. The basic tenets of reproductive health and justice promote the rights of women, men, their families and communities to lead healthy reproductive lives and advance the conditions necessary to exercise them. Already the issues have become more complicated and dynamic than ever with the advent of new reproductive technologies.

How do we establish policies in the area of reproductive genetics while simultaneously assuring reproductive autonomy? For example, while we stand firm on the rights of all women to choose whether or not to have a child, to continue wanted pregnancies to term and to access legal and safe abortions, how do we answer questions such as, “Does the right to choose whether or not to have a child extend to the right to choose the characteristics of a child (e.g., choosing the child’s sex or, in the future, possibly choosing eye color or other genetically determined traits)?”

Specific advocacy issues related to ART and reproductive genetics need to be addressed over the next decade. Some of these potentially thorny issues include:

- Lack of access to ART due to high costs or discriminatory policies [e.g., state or clinic restrictions on use by single women and men or lesbian, gay, bisexual, transgender, queer, questioning and intersex (LGBTQI) individuals and couples]
- Determination of what should be covered in public and private insurance plans
- Disputes over control and use of frozen embryos
- Anonymity of sperm and egg donors
- Assessment of whether payment to egg donors and surrogates is coercive
- Ethical and clinical issues related to “reproductive tourism” (in which individuals or couples travel abroad for fertility services due to lower prices or lack of regulation)
- Addressing federal bans and restrictions on embryo-related research and securing funding for research on reproductive genetics, the long-term health effects of ART and stem cells

Those working within the progressive advocacy landscape are increasingly challenged to develop a nuanced understanding of the benefits and risks of reproductive genetics, and they will have the opportunity over the next several years to advocate for policies that promote reproductive well-being for all individuals

and communities. Reproductive health care providers can help shape policies that respect and protect patients' rights while still ensuring men, women and families benefit from the advances in reproductive technologies and genetics research. And, while the reproductive health care community faces this changing world of reproductive science, they can do much to help patients understand their options and make the best decisions for the best possible care.

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