Rethinking Service Delivery with Regards to Reproductive Genetics

Traditionally, genetic counselors in prenatal care interface with patients only after they have been determined to be "high risk" due to family history concerns or tests such as carrier screening, aneuploidy screening and ultrasound. However, the current state of obstetrical care involves complex choices involving genetic testing for *all* pregnant women. The testing options available to women will only continue to grow with the expansion of new technology, and it is paramount that service delivery models adapt to the increasing complexity of testing choices.

Most healthcare delivery models do not support services that allow women to make informed and value consistent decisions about the growing array of available prenatal tests. Many in the field of obstetrics are recognizing the need for qualified experts to help patients navigate their options as genetic testing for all pregnant women continues to expand. We are often asked, "but are there enough genetic counselors?" It is likely impossible at this time to have every pregnant woman access one-on-one genetic counseling services, however there are creative ways to support patients and OB providers to optimize the patient experience and ensure that patients are making the best choices regarding genetic tests to meet their needs.

Prenatal genetic testing is typically used for reproductive planning and is intensely personal. While some women find the information that prenatal testing provides to be helpful for preparation or making decisions about pregnancy termination, some women feel very opposed to this information. We have done audits of prenatal genetic screening practices and have seen that in some cases 100% of patients undergo screening in one doctor's office whereas 0% of patients undergo screening when seen by the doc down the hall. So what is appropriate uptake for these optional tests? Well, that really depends on a number of factors – but for tests that have such personal meaning for different individuals it is difficult to imagine that 100% or 0% is hitting the mark of supporting patients to make informed, autonomous and value consistent decisions.

The challenges to informed consent in the current prenatal care model are numerous and complex. Given the pace of change in the fields of genetics, it is not surprising that the healthcare providers (obstetricians, midwives, family medicine physicians and their staff) tasked with discussing prenatal genetic tests often lack the expertise to obtain informed consent for these complex testing options. The current state of prenatal care often leads OB providers to recommend or encourage testing for their patients rather than to support individual choices through shared-decision support. Limited time and expertise coupled with a background of concern for a wrongful life suit are factors that may lead to favoring

testing, even if it is not in the best interest of the patient based on their individual needs and values.

The Genetic Support Foundation wants to change the way that women and couples are provided with information about prenatal genetic testing. One aspect of achieving this goal is developing and implementing standardized education programs for primary obstetrical care. Such programs can enable more informed decisions and reduce healthcare costs by supporting optimal utilization of testing.

Standardized genetic education may come in the form of online tools such as our NIPT video, but also may be print materials, in-person classes or webinars.

At the Genetic Support Foundation, we are committed to developing tools to optimize education about optional genetic tests so that patients can be empowered to make the decisions that are bets for them. Do you want to partner with us to change the way that we deliver prenatal genetic testing information? We'd love to hear from you.