Journal of Assisted Reproduction and Genetics (2019) 36:1767–1769
https://doi.org/10.1007/s10815-019-01522-w

MEETING SUMMARY

Proceedings of the New York University School of Medicine Reproductive Ethics Conference: Challenges and Solutions

Amani Sampson[1] · **Megan Sutter**[1,2] · **Arthur L. Caplan**[1,2,3] · **David L. Keefe**[1] · **Gwendolyn P. Quinn**[1,3]

Received: 26 June 2019 / Accepted: 2 July 2019 / Published online: 25 July 2019

The Reproductive Ethics Challenges and Solutions Conference was held on April 13, 2019, in New York, New York, and hosted by the Departments of Obstetrics and Gynecology, Medical Ethics, and Continuing Education at New York University Langone Health and School of Medicine. Drs. Quinn, Keefe, and Caplan organized a full day of expert speakers, as well as a screening of a documentary film about sperm donors and their children (Thank You For Coming) and a subsequent patient panel representing multiple perspectives: a “donor kid,” a male cancer survivor who used fertility preservation prior to his treatment, and a female unaffected carrier who used fertility preservation prior to prophylactic surgery. The sessions encompassed a broad range of timely ethical and legal issues related to oocyte and sperm donation; direct to consumer testing; elective oocyte and sperm cryopreservation; fertility preservation for patients facing gonadotoxic therapy; transgender and non-binary persons’ interest in family building; embryo screening; genetic engineering; male infant circumcision; insurance coverage for fertility preservation; mitochondrial DNA replacement; and uterus transplantation.

The educational objectives for the conference included:

- Identifying new reproductive technologies such as preimplantation genetic testing for hereditary disease, mitochondrial DNA replacement, and uterine transplant
- Identifying current ethical challenges associated with new and existing reproductive options
- Evaluating patient/provider communication in fertility preservation, and other assisted reproductive situations

New reproductive technologies

Dr. Paige Porrett, an assistant professor of Transplant Surgery at the University of Pennsylvania, discussed how her center developed a uterus transplantation clinical trial: Uterus Transplant for Uterine Factor Infertility (UNTIL) Trial. Dr. Porrett is co-principal investigator of the trial, which involves an interdisciplinary team of over 50 members from obstetrics, reproductive endocrinology, research, psychology, social work, pharmacy, nursing, bioethics, and transplant surgery. The goal of the UNTIL trial is to offer hope to cisgender women unable to give birth because they lack a functioning uterus. She described her own cognitive journey from initially viewing uterus transplantation as a risky approach to parenthood to eventually becoming supportive of patient autonomy for choosing to carry one’s own child. Prospective participants in the trial were assessed for both physical health and social support and must have been aged 21–40, non-smokers, and in general good health. The journey for each woman in the UNTIL trial will require as many as 150 medical procedures including biopsies and surgeries. While the typical woman has about 15 medical visits over the 40 weeks of pregnancy, UNTIL trial participants will have weekly visits for 2 years. The path to pregnancy may take anywhere from 16 to 24 months, and as with all assisted reproductive technology, there is no guarantee of live birth. Over 1000 applications were received and recruitment for the trial is now closed. During the discussion, questions were raised about safety monitoring during the trial.

Dr. David Keefe, professor and chair of the Department of Obstetrics and Gynecology at New York University School of

---

✉ Amani Sampson
amani.sampson@nyulangone.org

[1] Department of Obstetrics and Gynecology, NYU Langone Medical Center, 550 First Avenue, NBV 9N1-C, New York, NY 10016, USA

[2] Department of Population Health, NYU Langone Medical Center, New York, NY, USA

[3] Division of Medical Ethics, NYU Langone Medical Center, New York, NY, USA

Medicine, traced the rise and fall of mitochondrial replacement therapy (MRT). MRT is the replacement of mitochondria in one or more cells to prevent or reduce the impact of genetic disease originating from the mother. MRT uses healthy mitochondria from a donor egg. Dr. Keefe reminded the audience to use caution when presented with extrapolatory marketing equating preventing mitochondrial disease to treating oocyte aging—this argument is further detailed in a manuscript in *this edition*.

Oocyte cryopreservation is not new technology. However, with the declassification of egg freezing as experimental in 2012, new groups of women are opting for social or elective egg freezing. Dr. Pasquale Patrizio, professor and director of the Yale Fertility Center and Fertility Preservation Program, described how young women are pursuing elective cryopreservation at increasing rates, provoking an interesting discussion on the role of physicians in women's reproductive goal planning. Further, commercial companies promoting egg freezing often aggressively target young women and the reputability of these companies is unknown. Some companies seem to be offering misleading medical advice and statistics about success rates of live births from cryopreserved oocytes. The majority of young women who pursue elective oocyte cryopreservation are heterosexual and un-partnered, and the procedure offers the opportunity to build a career and search for a partner. Little is known about the long-term psychosocial consequences of freezing eggs that are either unsuccessful for a live birth in the future or that may not be used if a suitable partner/co-parent is not found. Additionally, women are not often counseled on age-related fertility decline when in their 20's and may misperceive their childbearing potential as lasting well into their 40's, when in fact it begins to precipitously decline at age 35.

Ethical challenges with new and existing assisted reproductive options

Dr. Loren Greene, an endocrinologist and clinical professor in the Departments of Medicine and Obstetrics and Gynecology at NYU School of Medicine, evaluated the role of paternal age in parenthood throughout animal and human history where the propensity for older fathers has been well demonstrated. She discussed emerging research on the association of sperm from older men with neurological and psychological disease in children. Presently, there are few considerations given to paternal age for couples undergoing assisted reproductive technology while there are many given to maternal age. Dr. Greene cautioned the audience that as the age of childbearing rises, reproductive endocrinologists will need to determine what regulation concerning eligibility for men is needed, if any.

Echoing the history of reproduction and concerns for regulation, Dr. Fino, assistant professor in the Department of Obstetrics and Gynecology, director of the Oocyte Donation Program, and associate director of the reproductive endocrinology fellowship program at NYU School of Medicine, discussed third-party reproduction with donor oocytes. The demand for donor eggs is greater than the supply, and there are limited regulations regarding egg donation. For example, presently there is no registry of egg donors and thus limited studies on their long-term health. Further, the lack of regulation regarding the amount of compensation an egg provider receives leads to potential for abuse and makes it challenging to ensure the donor is fully aware of all risks. These topics are further explored in her manuscript in *this edition*.

Andria Besser, a genetic counselor at NYU's Fertility Center, questioned whether we should test embryos for adult-onset genetic diseases, which is not currently standard practice. She emphasized the quandaries introduced by the use of preimplantation genetic testing for previously unknown conditions and variants of uncertain significance. She delves into this further in her manuscript in *this edition*.

Dr. Caplan, professor and founding head of the Division of Medical Ethics at NYU School of Medicine, took the audience on a journey through the history of the emergence of the concept of genetic counseling illuminating how the field of genetics has not reckoned with its eugenic past. Dr. Caplan presented both sides of the debate regarding the use of CRISPR and the potential for benefit as well as harm. Caplan asked the audience to consider what a disability truly is. Deafness? Left-handedness? Albinism? He further asked what our society may be like if there were no disabilities or "otherness." Caplan predicted reproductive endocrinologists and geneticists would soon be called upon to answer difficult questions about precisely when life begins and the role of genes in establishing personhood and personal identity.

Brendan Parent, a lawyer and director of the Applied Health at NYU School of Professional Studies, reviewed the current CRISPR editing controversy, which brought to light how little regulation currently exists both legally and medically. He encouraged the audience to question what the unintended consequences will be for children when we allow parents to edit embryos, which he considers in his manuscript in *this edition*.

Following the same vein of parental decision-making, Brian Earp, a doctoral student and associate director of the Yale-Hastings Program in Ethics and Health Policy at Yale University, explored the example of the regulation of male circumcision as decisions that parents make about children without their assent. Taking an innovative stand, he described how circumcision has become standard practice out of historical precedent rather than medical evidence. Furthermore, he noted how gender shapes how society perceives circumcision observing that in some ways male circumcision could be seen as a practice similar to female genital cutting, which is decried in the West as mutilation.

Evaluate patient/provider issues in fertility preservation, and assisted reproductive situations

Dr. Najari, a urologist, assistant professor in the Departments of Urology and Population Health, and director of the NYU male infertility program, reviewed the current methods of sperm retrieval and the challenges of retrieving sperm in an inpatient setting such as in the case of fertility preservation prior to gonadotoxic cancer treatment. He gave details about a newer population of patients—transgender women, who may consider sperm banking prior to beginning gender-affirming hormones and surgeries. He noted this could have some negative consequences such as heightened dysphoria.

Dr. Nahata, a pediatric endocrinologist and clinical assistant professor at Nationwide Children's Hospital in Columbus, Ohio, discussed her research assessing the acceptability of pursuing fertility preservation research with adolescent and young adult males with cancer. Nahata elaborated on the ethical issues that arise while doing research with vulnerable patients at a highly stressful time in their life. This research is detailed further in her manuscript in *this edition.*

Joyce Reinecke, a lawyer and executive director of the Alliance for Fertility Preservation, as well as a cancer survivor, shared her personal experience with fertility preservation as a survivor and updated the audience on the recent and ongoing health insurance coverage battle to provide all people undergoing medical treatment coverage for fertility preservation. Despite the American Society for Clinical Oncology evidence-based guidelines specifying that providers discuss the possibility of infertility and associated fertility preservation options with cancer patients, few people can afford to pursue fertility preservation due to lack of insurance coverage. At the time of this meeting, only five states passed legislation to require insurance to cover costs of fertility preservation in the case of iatrogenic infertility—including Connecticut, Delaware, Illinois, Maryland, and Rhode Island—with New York joining the list as of April 2019 thanks to advocates like Joyce. This leaves 44 states without a mandate, which also does not apply to companies with self-funded plans or federally funded programs like Medicaid or Tricare. Joyce continues to advocate for patient and provider awareness of fertility preservation and policy change.

During the mid-day portion of the conference, the audience watched a film, "Thank You For Coming," introduced by the Director/Producer/Star, Sara Lamm. The film explores Sara's journey to find her biological father more than a decade after learning she was conceived via sperm donor. Using online registries and the scant clues provided by her parents, we watched as she tracks down Jennifer, a woman sharing remarkable similarities who may possibly be her half-sister. Working together, they become genealogical detectives, navigating ancestry databases and DNA tests as they explore the meaning and power of family in this alternately funny and bittersweet personal film. After the film, Kelly McBride Folkers, a research associate at the Division of Medical Ethics at NYU, moderated a discussion of the film with Sara and the other panelists. The other panelists included three people with unique experiences with reproductive technology. The first panelist shared her experience knowing she was a "donor kid" from as early as she can remember. The second panelist talked about her decision to use fertility preservation in the wake of receipt of genetic test results and the opportunity to have this process covered by her employer. The third panelist walked the audience through his journey as a young adult, diagnosed with cancer in his 20's, and the importance of sperm banking to his goals for the future. The three panelists and filmmaker answered audience questions as well as specific questions from the moderator.

Dr. Sutter, a postdoctoral fellow in the Departments of Population Health and Obstetrics and Gynecology at the NYU School of Medicine, presented a review of sexual and reproductive health needs of transgender and gender-diverse individuals. Among the unique reproductive health risks discussed were impaired fertility due to gender-affirming treatments (e.g., hormone replacement therapy, gender-affirming surgery), lack of awareness of risk for sexually transmitted infections or pregnancy, lack of provider knowledge and training, and reduced access to care. An example of the infringement of reproductive rights of transgender individuals included the requirements of some states for proof of gender-affirming surgeries to change the sex marker on driver's license, which may limit reproductive capacity. A summary was presented of gender-affirming practices such as updating patient intake forms, training staff, using affirming language, providing reproductive care from preventing unplanned pregnancies, promoting sexual satisfaction to family planning, perinatal and postpartum health, and maximizing patient autonomy while minimizing distress.

Audience members left the day with a thorough catalog of ethical and legal issues emerging in the treatment of infertility and a better understanding of some of the policy responses intended to address them.

Acknowledgments Thank you Drs. Shaw, Yoder, Blakemore, Weidenbaum, and Friedlander with your assistance with reviewing manuscripts.