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INDEPENDENT ARTICLE: Struggles in Defining and Addressing Requests for "Family Balancing": Ethical Issues Faced by Providers and Patients

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Reporter

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Author: Robert Klitzman

Robert Klitzman, M.D., is a Professor of Psychiatry and the Director of the Bioethics Masters and Online Course Programs at Columbia University. He has written over 110 articles, and eight books, including *Am I My Genes?*, and *The Ethics Police?: The Struggle to Make Human Research Safe*.

Text

[*616] Introduction

Major controversies continue regarding whether and when assisted reproductive technology (ART) providers should perform preimplantation genetic screening (PGS) for sex selection for nonmedical reasons. Physicians may screen embryos for sex determination to prevent the transmission of serious sex-associated diseases, including conditions for which highly predictive genetic markers have yet to be identified. But, given disturbing rates of increased births of males over females in certain countries, ¹ concerns arise about a possible "slippery slope" when utilizing this technique, resulting in sexism and gender discrimination.

The American College of Obstetricians and Gynecologists (ACOG) in 2007 opposed offering sex selection for patients whose only reasons were personal (e.g., "family balancing") ² and not medical, yet stated, "Because a patient is entitled to obtain personal medical information about the sex of her fetus, it will sometimes be impossible for health care professionals to avoid unwitting participation in sex selection." ACOG affirmed its position in 2014. The Ethics Committee of the American Society for Reproductive Medicine (ASRM), however, stated in 2004 that while sex selection for social reasons (note: for simplification, unless specified otherwise, "sex selection" below refers to "sex selection for social reasons"), "should be discouraged," ³ sperm sorting, if found to be safe and

¹ K. Madan and M. H. Breuning, "Impact of Prenatal Technologies on the Sex Ratio in India: An Overview," *Genetics in Medicine* 16, no. 6 (2014): 425-432; A. Sen, "Missing Women," *British Medical Journal* 304, no. 6827 (1992): 587-588; The Geneva Centre for the Democratic Control of Armed Forces, "Women in an Insecure World. Violence against Women: Facts, Figures and Analysis," available at <http://www.unicef.org/emerg/files/women_insecure_world.pdf> (last visited October 25, 2016).

² Committee for Ethics, American Congress of Obstetricians and Gynecologists (ACOG), "ACOG Committee Opinion No. 360: Sex Selection," *Obstetrics & Gynecology* 109, no. 2 (2007): 475-478.

³ Ethics Committee of the American Society for Reproductive Medicine (ASRM), "Preconception Gender Selection for Nonmedical Reasons," *Fertility and Sterility* 82, Supp. 1 (2004): S232-S235.

effective, may be used for "gender variety in a family." ⁴ In 2015, the Ethics Committee of ASRM revised its opinion, stating that the committee lacked "consensus," but concluding that, "Clinics are encouraged to develop and make available their policies on the provision of nonmedical sex selection, and to accommodate employees' decisions about whether or not to participate in such treatment," and that providers are "under no ethical obligation to provide or refuse" it. ⁵

Opponents of social sex selection argue that it could lead to discrimination; that the long-term risks of PGS to mothers and children remain unknown; that such selection disrespects other embryos and children; and that it represents a slippery slope toward choosing other socially desirable traits -- and may thus border on eugenics ⁶ and that most of the public opposes it. In a US general population survey in 2004, 8% would use sex selection if it required 3-5 cycles of intrauterine insemination and cost \$ 2,500 per attempt, 74% opposed it, and 18% were undecided; and 18% would use it if it involved only taking a medication. ⁷ In response, supporters argue that it should be permitted ⁸ because of patient autonomy and reproductive liberty, and because it can help women who are pressured to have sons, ⁹ and need not be discriminatory, since preferences in the US for males and females are roughly equal, such that gender discrimination does not occur. ¹⁰

Data suggest that strong preferences may exist for males over females overall, and especially among certain ethnic groups, but are mixed among other populations. In one study, few women undergoing chorionic villus sampling and amniocentesis in general (i.e., not necessarily having any infertility problems) would approve of abortion for sex selection (19.2% for general population, and 5.3% for themselves). ¹¹ But in public opinion polls, Americans would prefer to have a boy, rather than a girl, if they could have only one child (40% vs. 28%). ¹² In 2002, 40.8% of US women seeking fertility care would select their next child's sex if it were free ¹³ and in 2007, 49% would do so, of whom 56% currently had no children. ¹⁴ Women with only daughters generally preferred sons while those with only sons preferred daughters. ¹⁵ Among patients undergoing Preimplantation Genetic Diagnosis (PGD), which look for specific gene mutations while PGS assesses the presence of correct numbers of chromosomes, 69% had no concern about it being used for sex selection. ¹⁶ Of 18 couples pursuing PGS for sex selection, 78%

⁴ Ethics Committee of the American Society for Reproductive Medicine (ASRM), "Use of Reproductive Technology for Sex Selection for Nonmedical Reasons," *Fertility and Sterility*, 103, no. 6 (2015): 1418-1422.

⁵ *Id.*

⁶ *Id.*; S. Wilkinson, "'Designer Babies', Instrumentalisation and the Child's Right to an Open Future," in N. Athanassoulis, ed., *Philosophical Reflections on Medical Ethics* (New York: Palgrave Macmillan, 2005): 44-69; V. Seavilleklein and S. Sherwin, "The Myth of the Gendered Chromosome: Sex Selection and the Social Interest," *Cambridge Quarterly of Healthcare Ethics* 16, no. 1 (2007): 7-19; S. Puri and R. D. Nachtigall, "The Ethics of Sex Selection: A Comparison of the Attitudes and Experiences of Primary Care Physicians and Physician Providers of Clinical Sex Selection Services," *Fertility and Sterility* 93, no. 7 (2010): 2107-2014; A. L. Kalfoglou, M. Kammersell, S. Philpott, and E. Dahl, "Ethical Arguments for and against Sperm Sorting for Non-Medical Sex Selection: A Review," *Reproductive Biomedicine Online* 26, no. 3 (2013): 231-239.

⁷ E. Dahl, R. S. Gupta, M. Beutel, Y. Stoebe-Richter, B. Brosig, and H. R. Tinneberg et al., "Preconception Sex Selection Demand and Preferences in the United States," *Fertility and Sterility* 85, no. 2 (2006): 468-473.

⁸ See Kalfoglou et al., *supra* note 6; J. Savulescu and E. Dahl, "Sex Selection and Preimplantation Diagnosis: A Response to the Ethics Committee of the American Society of Reproductive Medicine," *Human Reproduction* 15, no. 9 (2000): 1879-1880; E. Dahl, "The 10 Most Common Objections to Sex Selection and Why They Are Far from Being Conclusive: A Western Perspective," *Reproductive Biomedicine Online* 14, no. 1 (2007): 158-161; J. A. Robertson, "Preconception Gender Selection," *American Journal of Bioethics* 1, no. 1 (2001): 2-9.

⁹ See Puri and Nachtigall, *supra* note 6.

¹⁰ P. Collis, "Preimplantation Genetic Diagnosis for Gender Selection in the USA," *Ethics, Bioscience and Life* 4, no. 3 (2009): 16-22; N. Gleicher and D. H. Barad, "The Choice of Gender: Is Elective Gender Selection, Indeed, Sexist?" *Human Reproduction* 22, no. 11 (2007): 3038-3041.

preferred boys,¹⁷ feeling their preferences were ethical due to their desires for gender balance, limited family size and reproductive rights, though expressing some ambivalence about destroying embryos of the opposite gender, and about telling family members about their decision. Still, only 2 of these 18 couples ultimately utilized PGS, and the reasons the others declined are unknown -- possibly due to finances.¹⁸

Studies of ethnic differences are not entirely consistent, partly perhaps due to relatively few studies and small sample sizes. While Caucasian couples in one survey were split in their gender preferences, Chinese, Indian and Middle Eastern couples preferred males.¹⁹ In another investigation, patients seeking gender selection, overall, preferred males to females, especially Africans, Asian-Indian, and Chinese, while Caucasians and Hispanics preferred females.²⁰ Female Indian immigrants to the US seeking gender selection feel pressure to do so, often experiencing physical or verbal abuse otherwise, and 40% had terminated pregnancies with female fetuses.²¹

Yet studies of how providers view these controversies and in fact make these decisions remain very limited. Among 186 US ART clinics in 2006, 74% provided PGS, of which 42% did so for non-medical sex selection.²² On their websites, 18% of private clinics, but no hospital or university-based clinics, advertised social sex selection.²³ Among internists, neurologists, and psychiatrists, 5.2%, 7.6%, and 11.5%, respectively, would refer patients for PGS for family balancing, though 45.4%, 25.5%, and 23.5% were unsure.²⁴ In one English clinic in 2005, five discussion groups with a total of 23 staff working on PGS revealed challenges regarding how to balance patients' autonomy against the possible negative social effects.²⁵ In the US, interviews with 19 PGD service providers (4 nurses, 5 genetic counselors, and 2 each endocrinologists, geneticists, physician geneticists, embryologists, and laboratory directors) in 2003-04 found that they supported use of PGD for clear medical reasons but varied concerning social sex selection.²⁶ Among 15 physician sex selection technology providers (3 OB/GYNs offering ultrasound imaging, 6 physicians offering sperm separation, and 6 PGS providers), all supported non-medical sex selection, feeling that it respected women's autonomy and helped women who would be pressured to have male children, while primary care providers appeared to oppose social sex selection.²⁷ Yet ASRM suggests that the

¹¹ A. Kolker, B. M. Burke, and J. U. Phillips, "Attitudes about Abortion of Women Who Undergo Prenatal Diagnosis," *Research in the Sociology of Health Care* 9 (1991): 49-73.

¹² F. Newport, "Americans Prefer Boys to Girls, Just as They Did in 1941," Gallup, June 25, 2011, available at <<http://www.gallup.com/poll/148187/americans-prefer-boys-girls-1941.aspx>> (last visited October 25, 2016).

¹³ T. Jain, S. A. Missmer, **R.** S. Gupta, and M. D. Hornstein, "Preimplantation Sex Selection Demand and Preferences in an Infertility Population," *Fertility and Sterility* 83, no. 3 (2005): 649-658.

¹⁴ S. A. Missmer and T. Jain, "Preimplantation Sex Selection Demand and Preferences among Infertility Patients in Midwestern United States," *Journal of Assisted Reproduction and Genetics*, 24, no. 10 (2007): 451-457.

¹⁵ M. G. Katz, L. Fitzgerald, A. Bankier, J. Savulescu, and D. S. Crain, "Issues and Concerns of Couples Presenting for Preimplantation Genetic Diagnosis (PGD)," *Prenatal Diagnosis* no. 22, no. 12 (2002): 1117-1122.

¹⁶ See Missmer and Jain, *supra* note 13.

¹⁷ **R. R.** Sharp, M. L. McGowan, J. A. Verma, D. C. Landy, S. McAdoo, and S. A. Carson et al., "Moral Attitudes and Beliefs among Couples Pursuing PGD for Sex Selection," *Reproductive Biomedicine Online*, 21, no. 7 (2010): 838-847.

¹⁸ See Sharp et al., *supra* note 15.

¹⁹ See Collis, *supra* note 11.

²⁰ See Gleicher and Barad, *supra* note 11.

²¹ S. Puri, V. Adams, S. Ivey, and **R.** D. Nachtigall, "'There is Such a Thing as Too Many Daughters, but Not Too Many Sons': A Qualitative Study of Son Preference and Fetal Sex Selection among Indian Immigrants in the United States," *Social Science & Medicine* 72, no. 7 (2011): 1169-1176.

field lacks [*618] consensus -- i.e., that at least some providers oppose it. Hence, this ongoing disagreement, ASRM recommends that clinics develop their own policies, and make these available. ²⁸

Yet while the prior literature and guidelines have focused on whether social sex selection should be allowed or banned, ²⁹ the practice has nonetheless proceeded, raising crucial questions that remain unexamined concerning not *whether* it should be performed, but *when* exactly -- for which specific patients -- and how these decisions get made. Given this ongoing controversy, critical questions emerge of how providers and patients in fact now confront this issue on a daily basis, weigh these competing views, and make decisions in practice. Though ASRM has recommended that clinics develop policies related to social sex selection, many questions arise about how exactly providers manage and negotiate these conflicts and make these decisions; how they respond, if at all, to opposition to sex selection; whether they develop policies, and if so, what; and how they navigate in clinics where different views may arise. Given how little is known about this realm, these questions form the next generation of issues that need to be considered in this ever-evolving area. I thus decided to explore and elucidate these issues as part of a qualitative interview study on attitudes, decisions, and practices of ART providers and patients regarding critical ethical and related topics. These issues are of ever-increasing importance, given rising numbers of patients undergoing IVF in the US, Europe and elsewhere, and the fact that additional ARTs are being developed, and non-invasive prenatal-testing (NIPT) is marketed in over 60 countries and could be used for selection of gender as well as other non-medical and medical traits. ³⁰

Materials and Methods

In brief, as summarized on Table 1, and described briefly elsewhere, ³¹ I conducted 37 in-depth semistructured interviews of approximately 1 hour each with 27 ART providers -- 17 physicians and 10 other providers (7 mental health providers, 2 nurses, and 1 other) -- and 10 patients. One patient and three other providers were also themselves patients. Patients and providers were recruited through listservs, emails, and word-of-mouth. Providers

²² S. Baruch, D. Kaufman, and K. L. Hudson, "Genetic Testing of Embryos: Practices and Perspectives of US In Vitro Fertilization Clinics," *Fertility and Sterility* 89, no. 5 (2008): 1053-1058.

²³ **R. Klitzman**, B. Zolovska, W. Folberth, W. Chung, M. Sauer, and P. Appelbaum, "Preimplantation Genetic Diagnosis on In Vitro Fertilization Clinic Websites: Presentations of Risks, Benefits and Other Information," *Fertility and Sterility* 92, no. 4 (2009): 1276-1283.

²⁴ **R. Klitzman**, W. Chung, K. Marder, A. Shanmugham, L. J. Chin, and M. Stark et al., "Views of Internists Towards Uses of PGD," *Reproductive Biomedicine Online* 26, no. 2 (2013): 142-147; **R. Klitzman**, K. J. Abbate, W. K. Chung, **R. Ottman**, C. S. Leu, P. S. Appelbaum, "Views of Preimplantation Genetic Diagnosis among Psychiatrists and Neurologists," *Journal of Reproductive Medicine* 59, no. 7-8 (2014): 385-392.

²⁵ K. Ehrich, C. Williams, B. Farsides, J. Sandall, and **R. Scott**, "Choosing Embryos: Ethical Complexity and Relational Autonomy in Staff accounts of PGD," *Sociology of Health & Illness* 29, no. 7 (2007): 1091-1106.

²⁶ See Kalfoglou et al., *supra* note 6.

²⁷ See Puri and Nachtigall, *supra* note 6.

²⁸ See Ethics Committee of the ASRM, *supra* note 4

²⁹ Savulescu and Dahl, *supra* note 9; Dahl, *supra* note 9.

³⁰ S. Taylor-Phillips, K. Freeman, J. Geppert, A. Agbebiyi, O. A. Uthman¹, and J. Madan et al., "Accuracy of Non-invasive Prenatal Testing Using Cell-Free DNA for Detection of Down, Edwards and Patau Syndromes: A Systematic Review and Meta-analysis," *BMJ Open* 6, no. e010002 (2016), available at <<http://bmjopen.bmj.com/content/6/1/e010002.full>> (last visited October 25, 2016).

³¹ **R. Klitzman**, "How Old Is Too Old? Challenges Faced by Clinicians Concerning Age Cutoffs for Patients Undergoing In Vitro Fertilization," *Fertility and Sterility* 106, no. 18 (2016): 216-224.

were also recruited through national ASRM meetings (e.g., PGD and mental health provider interest group meetings). I approached attendees to ascertain whether they might be interested in participating in an interview study, and if so, I subsequently emailed them information about it. Most of those asked agreed to participate and did so. A mental health listserv was used, which is received by approximately 60 members (not all of whom are active), of whom 15 responded, and 8 were then interviewed. Additional interviews were conducted as background, for informational purposes, with 8 physicians, 9 mental health providers, and 14 patients; and informed, but were not included in, the final formal data analysis. Interviews for the formal data analyses were conducted with each group until "saturation" was reached (i.e., "the point at which

Table 1

Characteristics of Sample

	Male	Female	Total
Physicians	14	3	17
Physicians who are also patients	0	1	1
Type of Practice			
University affiliated	5	1	6
Private Practice	9	2	11
OTHER ART PROVIDERS	1	9	10
(e.g., mental health providers, nurses)			
Other providers who are also patients	0	3	3
Patients	1	9	10
TOTAL	16	21	37

[*619] no new information or themes are observed in the data").³²

Interviews explored participants' views and decisions regarding ethical issues concerning sex selection and other aspects of PGS and ART, and were systematically analyzed to obtain detailed descriptions of these issues. Providers described multiple patients they had treated, and interactions with colleagues; and patients often described interactions with multiple providers and other patients. From a theoretical standpoint, Geertz³³ has advocated studying aspects of individuals' lives, decisions, and social situations not by imposing theoretical structures, but by trying to understand the individuals' own experiences, drawing on their own words and perspectives to obtain a "thick description." The methods adapted elements from "Grounded Theory"³⁴ and were thus informed by techniques of "constant comparison" with data from different contexts compared for similarities and differences to see if they suggest hypotheses. This technique generates new analytic categories and questions,

³² G. Guest, A. Bunce, and L. Johnson, "How Many Interviews are Enough? An Experiment with Data Saturation and Variability," *Field Methods* 18, no. 1 (2006): 59-82.

³³ C. Geertz, *Interpretation of Cultures: Selected Essays* (New York: Basic Books, 1973).

³⁴ A. Strauss and J. Corbin, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (Newbury Park, CA: SAGE Publications, 1990); see Collis, *supra* note 11; Gleicher and Barad, *supra* note 11.

and checks them for reasonableness. I have used these methods in several studies examining key aspects of health behavior and doctor-patient relationships and communications in genetics and other areas.³⁵

I drafted the questionnaire (see Appendix for sample questions), drawing on prior literature. Transcriptions and initial analyses of interviews occurred during the period in which the interviews were being conducted, enhancing validity, and helping to shape subsequent interviews. Interviews were conducted via phone. The Columbia University Department of Psychiatry Institutional Review Board approved the study, and an information sheet that was sent to all participants, who then gave verbal consent.

Once the full set of interviews was completed, subsequent analyses were conducted in two phases, primarily by trained research assistants (RAs) and me. In phase I, we independently examined a subset of interviews to assess factors that shaped participants' experiences, identifying categories of recurrent themes and issues that were subsequently given codes. We read each interview, systematically coding blocks of text to assign "core" codes or categories (e.g., issues concerning gender selection using PGS; or ethical reviews of IVF-related issues). While reading the interviews, a topic name (or code) was inserted beside each excerpt of the interview to indicate the themes being discussed. We then worked together to integrate these independently-developed coding schemes into a single scheme. Next, we prepared a coding manual, defining each code and examining areas of disagreement until reaching consensus. New themes that did not fit into the original coding framework were discussed, and modifications made in the manual when deemed appropriate.

The RAs and I then independently content-analyzed the data to identify the principal subcategories, and ranges of variation within each of the core codes. We reconciled the sub-themes identified by each coder into a single set of "secondary" codes and an elaborated set of core codes. These codes assess subcategories and other situational and social factors, and included, for instance, specific reasons to perform or not perform social sex selection, and different types of ethics review (e.g., formal vs. informal; internal vs. external).

Codes and sub-codes were then used in analysis of all of the interviews. To ensure coding reliability, two coders (an RA and I) analyzed all interviews. Where necessary, we used multiple codes. We assessed similarities and differences between participants, examining categories that emerged, ranges of variation within categories, and variables that may be involved.

We examined areas of disagreement through closer analysis until we reached consensus through discussion. We checked regularly for consistency and accuracy in ratings by comparing earlier and later coded excerpts.

To ensure that the coding schemes established for the core codes and secondary codes are both valid (i.e., well grounded in the data and supportable) and reliable (i.e., consistent in meaning), they were systematically developed and well-documented.

In this process, we were able to explore "cases" of problems that arose (e.g., difficult decisions concerning sex selection) to examine the range and patterns of issues that emerged. We also examined data in the context of issues in the literature, posing questions and collecting sufficient details to substantiate points that arose.

Given that ASRM recommends that providers develop policies, and that scant data exist on how providers view these issues, and no prior research has been conducted on key aspects of their views and practices concerning

³⁵ **R. Klitzman**, D. Thorne, J. Williamson, W. Chung, and K. Marder, "Disclosures of Huntington Disease Risk within Families: Patterns of Decision-Making and Implications," *American Journal of Medical Genetics* 143A, no. 16 (2007): 1835-1849; **R. Klitzman**, P. S. Appelbaum, A. Fyer, J. Martinez, B. Buquez, and J. Wynn et al., "Researchers' Views on Return of Incidental Genomic Research Results: Qualitative and Quantitative Findings," *Genetics in Medicine* 15, no. 11 (2013): 888-895; **R. Klitzman**, "Institutional Review Board Community Members: Who Are They, What Do They Do, and Whom Do They Represent?" *Academic Medicine* 87, no. 7 (2012): 975-981; **R. Klitzman** and S. Daya, "Challenges and Changes in Spirituality among Doctors who Become Patients," *Social Science & Medicine* 61, no. 11 (2005): 2396-2406; **R. Klitzman**, "How Good Does the Science Have to Be in Proposals Submitted to Institutional Review Boards? An Interview Study of Institutional Review Board Personnel," *Clinical Trials* 10, no. 5 (2013): 761-766.

these issues (e.g., the processes by which they make decisions and how they act, given opposition to sex selection), this paper focuses on provider attitudes and practices, rather than those of patients.

Results

As seen in Figure 1, providers face a range of challenges and questions in making personal and practice-wide decisions about these issues.

Reasons for and against Social Sex Selection

Providers generally view sex selection for non-medical reasons as "family balancing," but vary in how they define it, whether they perform it, and if so, when, and how they make these decisions. While some providers raise objections, others dismiss these, and readily perform and justify their practice. ("I don't have a problem if a couple is doing family balancing, and would like to have a girl or a boy." [Physician # 11]) Providers all understood the relatively small risks of IVF and PGS, including a < 1% chance of Ovarian Hyperstimulation Syndrome (OHSS),³⁶ but many thus performed sex selection, feeling that the rationale for the procedure far outweighed the risks.

[*620] Figure 1 Challenges Concerning Sex Selection for Social Reasons

[*621] A few providers (mostly, though not exclusively women, and nurses and mental health providers) opposed or were wary of non-medical sex selection for several reasons: "gender is not a disease" [Physician # 1]; desires to plan one's offspring's characteristics pose concerns ("You really can't design kids." [Other provider-patient # 10]); and concern that boys may be unfairly preferred over girls.

Yet most providers supported social sex selection, often arguing that parents request boys and girls equally.

We get requests for just as many girls as boys, unlike China or India where everything is "boy." *That* would be scarier. I think it's fine to allow patients to decide. [Physician # 11]

Providers may dismiss the objection that sex selection represents eugenics, instead normalizing selection of social traits.

The eugenics arguments are very specious. We all practice eugenics in our choice of mate! Patients who would like to practice eugenics can go to the sperm bank, and get sperm from Michael Jordan, so they can have a basketball player. [Physician # 2]

Many providers also take a "free-market approach": from a business perspective, if patients want the service, doctors should provide it. In the current, highly competitive professional marketplace, physicians may have economic motivations. "Financially, we think: 'Should I just let it go through? Because otherwise, she's going to go down the street and do it.'" [Physician # 9] Yet clinicians may thus at times be conflicted by their interest in maintaining or enhancing profits.

Providers also respond to objections by arguing, for instance, that gender selection is easier to oppose in the abstract, than when seeing the details of particular patients.

People who aren't close to this, and don't see these people across the table may not understand it. When you look at patients from afar and are not involved with them, the first knee-jerk reaction is not to do it. [Physician # 10]

Challenges in the Content of Decisions

Defining Family Balancing

Yet doctors who are willing to perform sex selection for "family balancing" must then decide how exactly to *define* it: whether to set limits, and if so, where. Many providers draw certain lines, but these vary. At times, physicians cite clear instances where they think it clearly permissible, such as for relatively major, but not minor, gender imbalance

³⁶ D. Bodri, "Risk and Complications Associated with Egg Donation," in M. V. Sauer, ed., *Risk and Complications Associated with Egg Donation* (London: Springer-Verlag London, 2013): 205-219.

in a family -- e.g., for families with four children of the same sex. "When somebody has five boys and wants a girl, a part of me says, '*That's not unreasonable or crazy. They are not bad people.*'" [Physician # 4]

Other physicians adopt much lower thresholds -- e.g., selecting sex for a second, but just not a first child.

I have a tough time when the *first* child's gender is being selected. But if someone has a boy, and now wants a girl because they only want two kids, I have a hard time blocking that. I get it! [Physician # 2]

Other providers struggle with precisely *how* high a threshold to set, generally requiring that a family be *more* imbalanced. ("The procedure is definitely questionable when somebody comes in and wants a boy as a first or second baby. After that, it gets grey." [Other provider # 6])

Providers' Conflicts Concerning Sex Selection

Given these tensions, conflicts arise within and between clinics. Providers can remain uncomfortable, or uncertain regarding how best to decide, and can disagree. Clinicians may feel conflicted because their personal feelings and sense of professional duties clash, leaving them unsure how to balance or integrate these.

As providers, we always like to stay objective; but as human beings, it's hard to stay objective on those topics. To have somebody casually say, "*We're just going to discard those embryos*" doesn't feel right. At our physicians' meeting, we talk about the "ick factor": if it feels icky, we don't want to do it. [Physician # 9]

Even within one clinic, doctors' views may vary, without a unified formal policy. Some providers may refuse to do it, but refer patients to colleagues in their office. ("I just say I don't do it. Patients could go to another doctor in my practice. I feel I have to tell them that." [Physician # 14])

[*622] Various personal, professional, institutional, geographic, and other factors may shape doctors' attitudes and practices. ("It's done routinely in California, but tends *not* to be done electively a lot on the East Coast." [Physician # 3]) Among clinicians, women tended to be warier rather than men, concerned about possible preferences for males over females.

Clinics in which providers disagree vary in how then to proceed -- whether, and where they together set limits. ("I personally don't do it. I counsel against it. One other partner feels like me. But other partners disagree." [Physician # 13]) Yet their clinic has tempered the use of it. "We set the bar reasonably high." [Physician # 13])

How to Address Providers' Conflicts

Given these reasons, many providers seek various strategies, establishing parameters or pursuing compromises. For instance, clinicians may practice sperm sorting (though it is not as effective as PGS), seeing it as less egregious than PGS. Compared to embryos, sperm are less constituent of life itself, and thus have less moral status *per se*. Other clinicians agree to select sex only if the patient is undergoing IVF anyway, and without promises of necessarily obtaining the desired gender:

We have done PGD for gender selection once or twice, but with the understanding that if they don't have any healthy embryos of the gender they want, yet do have healthy embryos of the other gender, we will use them. [Physician # 7]

Providers may also seek compromises by transferring one embryo of each gender. Yet this approach can still generate controversy among staff.

The only way we've kind of gotten around this is having patients agree to transfer one embryo of each gender. Then, they're still "leaving it up to God," but at least know they had a male embryo transferred...Some staff in my practice say we're being ridiculous, because if the parents wanted a boy, and only have a girl, she's going to have a "horrible life." [Physician # 9]

Thus, within a clinic, providers may face difficult tensions and tradeoffs.

Other clinics may seek to navigate these controversies by claiming they are performing PGS for reasons *other* than sex -- e.g., checking for chromosomal abnormalities.

Facilities say they're screening for aneuploidy, and "Oh, by the way it's a girl," or "it's a boy." So the excuse was aneuploidy -- the *reality* was that it was gender selection...everybody knows the couple came in asking for gender selection." [Other provider # 6]

Given these conflicts, providers may remain uncertain about their beliefs regarding social sex selection. "I'm not convinced there is a 'right' answer." [Physician # 7]

Challenges in the Process of Decision-Making

Whether to Have a Formal Ethics Review?

Not only the content, but the *process* of decision-making varied widely. Overall, larger hospital- and university-affiliated clinics appeared more likely to have formal external ethics committee reviews than did smaller and private free-standing clinics. Yet, these committees' review processes ranged widely in whom they included, and how they worked -- from formal to informal, and from internal to external.

The biggest ethical issue that we faced with PGD was gender selection for family balancing....We had about *two years of ethics committee meetings*, and after a long period reached a consensus... Some places do it, but we don't. It's non-negotiable. [Physician # 3]

[*623] The first time an ethics committee outside a clinic itself confronts this issue can involve a long and intricate decision-making process, since these discussions may include outsiders, other than ART clinicians. Such committees may discourage social sex selection, both generally and regarding specific cases. When a university-affiliated clinic faced a patient with three or four girls, who wanted a boy: "We dealt with that through the ethics committee, to make sure we were doing the right thing. In general, we are not proponents of sex selection." [Physician # 8] His ethics committee also examined sex selection for ostensible medical rather than elective, social reasons. "We have done PGD for gender selection for autism, but that issue also went to the ethics committee." [Physician # 3] A few academic medical centers even have a hospital ethics committee dedicated *exclusively* to ART.

When ART started here...the program was set up through the hospital ethics committee. The committee rapidly decided that it did not have expertise in this area and suggested an offshoot -- an ethics committee specifically designated to look at assisted reproductive issues. The hospital ethics committee specifically looks at things like end-of-life decisions. It's like a court. On at least two occasions -- once for gender selection using PGD -- our ART ethics committee had an impasse and took it to the hospital ethics committee, which also had an impasse and sent it back to us; but those discussions were helpful, and we then reached a solution. [Physician # 3]

Clinics in academic medical institutions can also differ from others in having not only more external and systematic ethics reviews, but other, indirect interactions that can serve as *de facto* ethical reviews.

Affiliation with a university or hospital can only have a beneficial effect -- just being exposed to a university. A lot more peer review and thought go into one's practice. Doctors have to stand up and present their own data, and justify why certain things were done. *That* makes it much more difficult to be entrepreneurial. We present our data all the time, not necessarily to an ethics committee, but in front of our faculty. Our residents rotate through our program, so they're always seeing exactly what's happening...It's a *check and balance* to know what's going on, as opposed to just doing it and advertising about it without any oversight. [Physician # 12]

Free-standing clinics may be more "entrepreneurial, while institutions are typically very much against it." [Physician # 10] Ethical reviews can thus range across a spectrum from formal to informal. Given these processes, many academic institutions, and especially their external committees, frequently resist sex selection.

What Criteria to Use?

Questions arise of how ethics committees themselves operate -- which cases clinicians present (all or only some -- and if so, which), and how exactly these boards then decide (e.g., what standards and criteria they use).

If the parents have four boys and want a girl, I bring it to our ethics committee and we talk about it. The screening we use is the "sniff " test: is this totally comfortable? [Physician # 4]

Committees may thus base these decisions on intuitive, subjective factors, rather than explicit ethical analysis. Doctors frequently seek various criteria or tests: e.g., how the decision would look in the news.

I call this "the newspaper headline approach" to ethical decision making: how comfortable would we be if we're on the front page of the local newspaper, with the headline that our program decided to do elective sex selection or not? I'm comfortable if the reporter puts into the article that we at least vetted the process very completely. [Physician # 3]

Who Makes the Decisions?

Decision-making processes can differ in how *systematic* they are, and who is included -- whether and how many non-ART providers participate.

Our ethics committee includes community people, ethicists, physicians, geneticists, psychiatrists, social workers, and a judge. The hospital administration was involved. It was a two-year process. Whatever outcome we reach, we've thought it through extraordinarily carefully, and audited all of these processes, and collected minutes for all those meetings. You can disagree with the conclusion, but it would be hard to disagree with the *process*. That gives us both a level of discussion and safety, instead of "*I'm a single practitioner doing IVF in a rural area. I'll make it up, and decide by myself that I'm doing this.*" [Physician # 3]

[*624] Especially since the outcomes of these decisions can be controversial, the process can thus be important in seeking procedural fairness.

Private and/or smaller clinics, unaffiliated with academic medical centers, may lack formal ethics committees and instead simply have some or all of the physicians and staff discuss difficult cases. These conversations range in scope, length, inclusiveness and formality, and how much they set or refer back to ongoing formal policy or precedent. Physicians and staff may have no formal ethics training.

If you want to go outside the rules, we have the nurses, the nurse managers, the doctors, the lab director, and the psychiatrist sit down and talk about it. But we *can't expend a tremendous amount of effort on one patient, trying to assuage their cultural reality.* [Physician # 9]

These decisions may hence be made case-by-case, rather than through the development of a broader formal policy.

The amount of oversight and feedback may increase with the size of the office. Doctors working individually or in very small practices may thus receive even less oversight,

On these sticky topics, most people in a reasonably-sized practice figure it out on their own. We're four doctors. The one- or two-doctor shops may have less inter-professional oversight. [Physician # 9]

Clinics can thus differ regarding not only whether they are university-affiliated or private but, especially among the latter group, whether they are large or small.

Other clinics may refer these decisions to a committee focused not on ethics, but on quality assurance.

Anybody who asks for gender selection for social reasons has to bring it to the quality assessment committee in our practice, which includes the physicians, nurses, and lab people. The doctor has to make a case about why we should consider it. [Physician # 13]

At other clinics, the decision-making process may mostly involve consultation with a mental health professional. ("Our family-balancing couples go to psych and make a decision." [Physician # 9]) Yet at other private offices, these decision-making processes may remain vague or unclear -- even to staff. Mental health providers, for instance, may not be involved with these deliberations at all, or even be aware how decisions are made. "I don't know how they make those decisions. That's a good question." [Other provider-patient # 10]

Advantages and Challenges of Policies

The development and establishment of clear policies and procedures can offer certain advantages -- more clarity and less confusion.

If it's a larger clinic, and they have an ethics review board and/or policies and procedures, they're probably *better off*. If you're a smaller clinic, all sorts of things come up. Ethical issues are really big in infertility. [Other provider # 5]

Bigger practices may end up having certain advantages in establishing more explicit or thorough policies, aiding clinicians who may want to refuse sex selection requests.

It would be much easier for me if we had a policy against doing it. I could just say, "I'm so sorry. I wish we could do it. But we have a policy against it." Since we don't have that, it puts me in a very difficult position. I have to say, "No, I don't believe in this, so you can see one of my colleagues and do it." That's very hard. [Physician # 14]

Conversely, certain doctors might be willing to perform social sex selection, but cannot because their clinic's policy opposes it.

Personally, I don't have any problems with gender selection for social reasons, but our hospital will not let us. I would have no problem, particularly if the patient is going through IVF anyway. Even if the patient didn't, I wouldn't have a problem for family planning and balancing. But it doesn't bother me not being able to do it. [Physician # 10]

Providers vary widely in not only the nature, but also in the *strength* of their preferences either pro or con.

Systematic vetting by a committee can also take a while, postponing treatment. "The downside is time -- my time and other people's time. That process can take three or four months. This couple is waiting to do IVF. That's a long time." [Physician # 3] The length of this decision-making process can range, however, depending partly on how new vs. familiar the dilemma is for the group. "The chair of our committee is now one of the hospital attorneys. He is relatively new in that role -- about a year -- and is kind of a novice at it. There's a long learning curve." [Physician # 3]

[*625] While such consultation can delay patients, they may understand, given the issue's complexities. One physician told a couple, "It's going to take me a month to get back to you. The couple were both teachers, and they liked that approach -- very reasonable and fair." [Physician # 4]

Opposition to Government Regulations

While many countries explicitly prohibit social sex selection, most US providers, even if personally troubled by it, opposed the introduction of government regulations. Nonetheless, some clinicians, especially women, remained ambivalent and unsure whether current policy was adequate.

I usually like having fewer policies. Yet, some things beg for oversight. I don't know how I feel about the little boys getting let go, and the little girls being given a chance at life. [Other provider-patient # 10]

Nonetheless, even providers wary of sex selection tended to oppose laws banning it. Rather, they supported the current system of looser, essentially unenforced guidelines. Many patients, too, hold this view: even if personally against social sex selection, they were often leery of government prohibition.

I don't agree with such laws. Similarly, I don't think we should pass laws against abortion. Every case is different. Just because someone's using a technology in what I believe is the wrong way, doesn't mean it should be against the law. If autism is in the family, and the parents are worried that a boy might be more autistic than a girl, so they'd rather have a girl, having a law is a bad idea. [Patient # 7]

Discussion

These data -- the first to explore several critical dilemmas and challenges that ART providers confront in making decisions about social sex selection -- highlight several key challenges and questions. While ASRM's Ethics Committee failed to reach consensus concerning such sex selection, and recommended that clinics each develop their own policies, the present data suggest how clinicians may struggle to do so. The past literature has presented lists of arguments for and against social sex selection, and found that providers differ in *whether* they think sex selection is ethical or not. Yet no prior studies have examined *how* clinicians then in fact seek to balance these competing issues, and make these decisions, and vary in doing so. The present data suggest how clinicians face several specific struggles -- concerning how to define "family balancing," when precisely to offer it, what specific

thresholds to establish, how firmly to do so, how much "family imbalancing" warrants sex selection (e.g., whether providers should select sex for all patients who request it vs. only for patients seeking it for a second vs. for a third or fourth child), what criteria to use in making these decisions, whether to seek compromises, and if so, how, what decision-making processes to use, and who exactly should develop such policies. Providers differ in these decisions, and where they draw these lines -- e.g., how exactly they define acceptable "family balancing" and proceed when colleagues [*626] in the same clinic disagree -- whether to let majority rule vs. let providers each proceed as they wish. Though many providers may prefer PGS for sex selection over selective abortion of fetuses based on sex (since abortion is more invasive and involves termination of a fetus, which is far more developed than an embryo), questions still arise of whether to perform PGS for sex selection, given the ethical dilemmas involved.

The present data are the first to explore, too, the *processes* by which clinicians make these decisions, illustrating how these processes can vary widely in structure, flexibility and formality, and how achieving consensus within clinics is not always easy.

While proponents argue that sex selection is ethically permissible among US patients because the demand for boys and girls are roughly equal,³⁷ the present data suggest that some patients may prefer females to avoid having children with autism or other male-linked diseases. Couples are choosing boys, however, for purely social reasons. Sex selection based on social bias against girls may thus still occur, raising concerns.

These data suggest, too, that patients may claim that they are interested in pursuing sex selection because of concerns about risks of familial disease with an unequal gender ratio (e.g., autism), when that may not be the real reason they are interested. Thus, providers should consider not only asking, but checking patients' statements regarding these family medical histories.

Understanding these decision-making challenges and the processes involved can aid providers in several ways. Given that many clinics are now in fact selecting sex, attention and debate are needed concerning not only *whether* the practice should be allowed, but also *when* exactly it may be acceptable or not, and *how* these decisions are and should be made. How clinics decide *when* to perform sex selection may depend partly on the relative strength of each provider's view, but also on the respective roles of the clinicians who may be disagreeing. Physicians may overrule nurses, mental health professionals, and others. Doctors earning income through sex selection may also be conflicted and/or biased in their perspectives. The limited research exploring provider attitudes has not examined this phenomenon, but should do so.

The current data underscore how providers often wrestle with these tensions (e.g., concerning how and to what degree to weigh patient autonomy against broader social concerns as well as their own beliefs and motives), and whether to seek compromises, and if so, what. Balancing such competing ethical principles can be difficult, pitting clinicians' personal moral intuitions against their perceptions of their professional responsibilities. Clinicians' personal feelings may stem from concerns about beneficence toward the unborn child and potential broader social inequalities. In brief, providers appear divided on whether to prioritize patient autonomy (i.e., desires for sex selection) vs. potential harms (e.g., to the unborn child) and social justice (i.e., promoting eugenics); and may be biased due to conflicts of interest (i.e., gaining financially from more patients wanting sex selection performed). These data reveal how providers may respond when ethical principles thus conflict, and no consensus has been reached. Many clinicians then wrestle with a lack of clear "objective" means for determining which approach is unequivocally "correct"; and respond to these ethical tensions in several ways -- by rationalizing or seeking to justify a position, seeking compromises (e.g., by choosing one embryo of each sex; allowing selection if the gender imbalance is relatively high, rather than low; or deferring the decision to a committee), or seeking criteria or ways of deciding (e.g., the "sniff test", or the "newspaper headline test"). Physicians may seek to rationalize or justify their decisions when facing conflicts of interest. To balance tensions between autonomy, beneficence and justice,

³⁷ See Ehrich, *supra* note 33; Gleicher and Barad, *supra* note 11.

notions of "relational autonomy" have been proposed,³⁸ emphasizing that individuals are "inescapably constituted through relational networks."³⁹ Yet, in fact, bioethical debates often involve critical needs to weigh competing ethical principles (e.g., autonomy vs. beneficence and justice).⁴⁰ Difficult ethical decisions invariably involve such conflicts between principles.

These data reveal how providers may respond when ethical principles conflict, and no consensus has been reached. While some clinicians readily proceed, favoring one side of the debate, others remain unsure. Many clinicians wrestle with a lack of clear "objective" means for determining which approach is unequivocally "correct"; and respond to these ethical tensions in several ways -- by rationalizing or seeking to justify a position, seeking compromises (e.g., by choosing one embryo of each sex; allowing selection if the gender imbalance is relatively high, rather than low: or deferring the decision to a committee), or seeking criteria or ways of deciding (e.g., the "sniff test", or the "newspaper headline test"). Physicians may seek to rationalize or justify their decisions given conflicts of interest, paid by patients seeking sex selection.

Whereas research on patients undergoing IVF for infertility generally shows that they have mixed opinions about PGS use for sex selection, the present data suggest that providers themselves nonetheless commonly see patients who wish to select the future [*627] child's sex. Thus, while most of the tens of thousands of patients undergoing IVF each year may not want or opt to choose the child's sex, a definite proportion, even if constituting a relative minority overall, are nevertheless interested in doing so.

Though ASRM guidelines state that clinics should develop and make available written policies, these data highlight the challenges that can emerge concerning not only the content, but the *processes* involved -- whether not only physicians, but nurses and mental health providers should be involved, and if so, whether these non-physicians who might resist sex selection in certain situations (e.g., if a patient now has only one child) will feel comfortable opposing physicians who may support sex selection in such instances. Professional organizations (such as ASRM) and others should consider addressing when social sex selection is acceptable or not -- perhaps permitting it for a family that already has four but not just one child of one sex, and stipulating that non-physicians should be involved in these decisions. These data suggest that mental health providers and, potentially, lawyers can help in sex selection decisions, not just physicians. Different decisions may also result when such outsiders are involved who are not financially benefitting from the procedure, and may thus consider the social costs more fully. Questions arise of whether individuals external to the ART clinic should also be routinely included in developing clinic policies. In academic institutions, such external individuals are regularly parts of clinical and research ethics committees. Transparency and clear thresholds may be beneficial as well.

These data highlight several directions for future research -- e.g., to examine, among larger samples, the types and ranges of clinicians' behavior -- how often clinics in fact develop and make available their policies; how these differ, and what factors (such as personal and professional characteristics of providers, and the nature and size of their practice) may play roles; how often practices let majority rule vs. have physicians each decide for themselves; how often clinicians who refuse to offer sex selection instead give patients referrals to colleagues who may offer it; and whether these colleagues always end up filling such requests, and if not, when they refuse to do so (e.g., sex selection for a first or second child). Such research can assist providers in the field in assessing and balancing these competing issues, and in developing, refining and encouraging "best practices." Future research can also examine whether and how various subsets of patients may differ -- e.g., those who learn fetal sex while undergoing PGD for medical reasons (because of risks of transmitting a lethal mutation) vs. those who are only selecting sex; and whether and how providers respond differently to each group. These data suggest needs for research on what

³⁸ C. Mackenzie and N. Stoljar, "Introduction: Autonomy Reconfigured," in C. Mackenzie and N. Stoljar, eds., *Relational Anatomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (New York: Oxford University Press, 2000): 514-533.

³⁹ See Ehrich, *supra* note 23; J. L. Scully, T. Shakespeare, and S. Banks, "Gift Not Commodity? Lay People Deliberating Social Sex Selection," *Sociology of Health & Illness*, 28, no. 6 (2006): 749-767.

⁴⁰ T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics* (Oxford/New York: Oxford University Press, 2008).

ethics training clinicians have had, both generally and regarding genetics and IVF; whether, when, and how often clinicians draw on explicit ethical principles vs. implicit moral intuitions or "yuck" responses; and what factors, if any, including gender and aspects of providers' training are associated with differences in their attitudes or practices concerning sex selection. These issues could also be explored further among other groups more broadly in society, though fertility clinics are where critical decisions about sex selection are in fact getting made.

These data also highlight needs for education of providers, policymakers, and others concerning these issues. Providers would benefit from increased training and awareness concerning these ethical dilemmas and ways of addressing them -- how to weigh, evaluate, and make these decisions.

Given the contentiousness of these issues, clinicians should consider and weigh not merely the patients' autonomy alone, but the other competing principles entailed (e.g., the best interests of the unborn child, and the broader social costs). Moreover, given the fundamental clash of principles involved, full consensus may be impossible. Additionally, while some commentators have focused on autonomy and beneficence,⁴¹ the additional critical bioethical principle of justice also plays crucial roles here, given concerns about broader possible societal effects of sex selection. Guidelines concerning appropriate decisional content and processes from professional organizations, scholars and others can be helpful here. At the same time, clinicians should be aware of their possible biases in these decisions.

The fact that NIPT is increasingly used for selection of a wide variety of genes⁴² makes these issues especially salient. These data suggest that in the future, both providers and patients may range widely in what specific genes they want NIPT to detect (i.e., associated with other non-medical or medical traits) and how frequently, how often they terminate pregnancies as a result, why they do or do not test for each gene, how they respond to ethical conflicts that surface, and how they decide -- based on what criteria and kinds of review. Guidelines may also be valuable, though decisions will need to be made concerning what and how specific guidelines should be developed.

These data have several potential limitations. The sample size is sufficient for qualitative research to elucidate the issues and themes that emerge, but future studies using larger samples can examine statistically how different groups (e.g., physicians in different geographic regions) may vary, and exactly how prevalent **[*628]** each of these attitudes and behaviors are as a whole among providers, and how much impact each of these various factors may have. Though it is potentially conceivable that providers with certain attitudes may have been more likely to participate for some reason, the interviewees here demonstrated a full range of attitudes (e.g., both for and against sex selection, for a variety of reasons). Nonetheless, future studies using larger samples can explore such possibilities more fully. The current qualitative study, as the first to explore several key aspects of this topic, was designed to probe the issues and themes that emerge, not to calculate statistically how providers in various settings (e.g., academic hospitals vs. private clinics) differ, and the "relative frequencies" of practices and views among these various groups. Nonetheless, these data, as the first to explore many of these critical issues, provide vital and unique insights that can be critical in designing future studies to explore these issues among larger samples. Still, clinicians are very busy, and recruiting larger numbers of them can pose challenges, no doubt accounting in part for the astonishingly low number of such studies published to date.

In sum, these data thus shed important light on how physicians, other clinicians and patients make decisions about sex selection through PGS, and have important implications for enhancing future practice and guidelines.

Appendix A

Sample Questions for Providers

. Have you recommended PGD/PGS to patients? Why or why not?

⁴¹ See Puri and Nachtigall, *supra* note 6.

⁴² See Taylor-Phillips et al., *supra* note 28.

- . How did you make these decisions?
- . When have you recommended PGD/PGS? For what indications? How often have you done so?
- . How often in the past year? In the prior year?
- . Have you ever decided not to support use of PGD/PGS? How did you make that decision?
- . Do you have concerns about patients using PGD/PGS? If so, what?
- . What changes if any, have occurred over time in your PGD/PGS use?
- . What additional thoughts do you have about these issues?

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