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**Views of Genetic Counselors on the Use of PGD
for Social Sex Selection Purposes**

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*Submitted in partial completion of
the Master of Science Degree at Sarah Lawrence College*

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Table of Contents

Abstract

I.	Background.....	1
	a. Ethical Issues and Terminations.....	2
	b. Population Imbalance.....	2
	c. Family Balancing.....	4
	d. Slippery Slope.....	4
	e. Laws.....	6
	f. Previous Studies.....	7
II.	Methods.....	9
III.	Results.....	9
IV.	Discussion.....	15
V.	Conclusion.....	21
VI.	References.....	22

Abstract

Preimplantation genetic diagnosis (PGD) allows genetic information to be tested after an egg is fertilized in vitro before implantation into the uterus. The technology was first used to select for embryos at risk for X-linked diseases, however it has been observed that prospective parents are using this technology to select for the sex of their child based on preference. This study aims to examine the views of genetic counselors towards the use of PGD for social sex selection purposes. A survey was conducted using the online website survey monkey's platform and sent to members of the National Society of Genetic Counselors through their eblast. A majority of the respondents expressed that they were worried about the potential future of sex selection leading more offensive types of trait selection, and they feel that the use of reproductive technology to select trait is likely to become more commonplace over time. They showed discomfort in counseling patients about social sex selection regardless of the patient's age, ethnicity, or reasons such as family balancing. Genetic counselors did not support termination of pregnancy for sex selection purposes, but felt strongly in the right of the patient to terminate a pregnancy regardless of the reason. Genetic counselors are concerned about their role in the current practice regarding social sex selection. 1. They have conflicting views that on one hand, they do not support pregnancy termination for social sex selection purposes, but on the other hand, they believe the right of the patient in terminating a pregnancy for any reason. The result of this study suggests that perhaps a formal discussion should take place to explore the role of genetic counselors in this emerging area of patient service.

Background

Preimplantation genetic diagnosis (PGD) is a medical technique by which prospective parents can inform themselves about the genetic makeup of early embryos. In some instances, it can be used for the purposes of sex selection, either for medical purposes or to obtain a child of the desired sex. PGD's first use was as a tool for sex selection, to select among embryos at risk for an X-linked disease (Delhanty, J. D., 1994). For most X-linked diseases, male embryos are at a 50% risk of being affected, and female embryos are at a 50% risk of being carriers. Therefore, female embryos only were selected and implanted into the prospective mothers.

Since it first was developed in the 1980s, PGD has been used to select for single gene disorders such as Myotonic dystrophy, Huntington's disease, Fragile X, B-thalassemia, retinoblastoma, and spinal muscular dystrophy (Verlinsky, Y. et al, 2004). These uses have not been free of controversy. Some argue that its use suggests a lack of respect and tolerance for people with disabilities (Macklin, R., 2010), while others believe that the pain and suffering experienced by children with genetic conditions and their families should triumph over all other arguments (Botkin, J. R., 1998). Questions have been raised about where and how to draw the line on the use of PGD, with some suggesting that it be restricted and others deferring to the autonomy of the prospective parents in all situations (Macklin, R., 2010).

Ethical Issues around Terminations

PGD can be seen as unethical because it involves creating and discarding embryos. There are different stages of life, and the timing of any form of prenatal testing could make a significant difference in its ethical implications. It has been argued that a 3-day old embryo is not the same as a 5 month old fetus, and hence discarding embryos and terminating fetuses should be viewed differently (Botkin, J. R., 1998; El-Toukhy, T. et al, 2008). PGD allows parents concerned about a risk of genetic disease to know ahead of time that the baby is unaffected, so that the anxiety associated with waiting for a prenatal diagnosis is avoided. It also should be noted that all pregnant women have the legal right to terminate their pregnancy for any reason before the legal cut-off time, which most of the time in the United States is 24 weeks gestation. However, whatever one's stand on abortion, it is generally agreed that for ethical and medical reasons, earlier termination – or the loss of an embryo before implantation– is a better outcome than a late termination.

Population Imbalance

The use of this technique for social sex selection has raised its own ethical issues. Many argue that social sex selection is an act of sexism, and that the use of PGD for social selection provides no therapeutic benefit to the child (Robertson, J. A., 2001). Selection in favor of male fetuses is far more common worldwide, as seen in many countries where social sex selection practiced through termination has lead to population imbalances.

In China, ultrasound technology became readily available to the public in the 1980s, and abortion for the purpose of sex-selection following prenatal ultrasound became a popular method to ensure the birth of a son. The widespread use of this practice can be inferred by a look at sex imbalances in the population. It is estimated that there will be an excess of 22 million men of reproductive age in China by 2025, and the consequences of this have already been felt (Greenhalgh, S., 2013). Problems with “bride trafficking” have come to the government’s attention, with girls in rural areas being kidnapped and traded to other rural areas as brides to single men (Li SZ, Yan SH., 2008; Zhou, C., 2012).

In India, the first national analysis of sex-selective abortion trends, published in 2011 (Jha, P., 2011), reported sex ratio differed significantly depending on the sex of the firstborn. Between 1991 and 2011, when the firstborn was a girl, the child sex ratio (number of females to every 1000 males) for ages 0-6 dropped by 1.5% on average. However, the child sex ratio for a second child did not differ from predicted norms when the firstborn was a boy. By 2011, there were 7.1 million more boys between the ages of 0-6 than girls (Jha, P., 2011). The study also found that preference for sons had no relation to socioeconomic status, but selective abortion did. More educated women from richer families were more likely to use sex-selective abortion. This difference was attributed to greater access to medical services (Jha, P., 2011).

The availability of PGD could worsen the population imbalance problems in countries such as India and China. However, wide scale use of PGD for sex selection might not be feasible in these countries for financial reasons, and the increased population

imbalance that is feared might not be relevant (Macklin, R., 2010). The cost of a cycle of IVF cycle with PGD including the medication for the induction of ovulation is approximately \$17,000 - \$20,000 USD (Sherbahn, R., Accessed 2014).

Family Balancing

Family balancing is an aspect of the use of PGD for social sex selection that is arguably more likely to be accepted by the general public. Proponents suggest that it is not the desire for one sex over the other but a boy-girl balance that parents are seeking (El-Toukhy, T. et al 2008; Macklin, R., 2010; Pennings, G., 1996). Family balancing is less likely to be seen as sexist because parents with one or two children of the same sex want a child of an opposite sex. If psychological studies support that there are biological differences between girls and boys, then arguably those interested to experience both should not be discouraged because of concerns about discrimination (Sermon, K. et al, 2004). On the other hand, family balancing brings up the question of stereotyping gender. There's a possibility that parents may put unnecessary pressure on the child to abide by gender stereotypes, and the disappointment in failing to meet such expectations may affect the parent-child relationship.

Slippery Slope

A public opinion survey done in 2004 with a representative sample of 4,834 Americans showed that 66% agreed with the use of PGD for fatal medical conditions, but a majority expressed concerns about the idea of “designer babies” and distrust in the morals of scientists developing advancements in technology. 53% agreed or strongly

agreed that “scientists these days don't pay enough attention to the moral values of society” (Hudson, K. L., 2006). Concerns expressed about the “slippery slope” potential of PGD include the development of two classes of people in the future: the genetically enhanced and the non-genetically enhanced. The average height, intelligence etc. would be raised higher, rendering the non-genetically enhanced increasingly at a disadvantage. The cost of PGD technology selects for a richer population, making the rich richer with genetically enhanced “designer babies” (Brenner, D., & Brutlag, D., 2013; Hudson, K. L., 2006).

Another concern expressed by Brenner and Brutlag is related to the welfare of the genetically enhanced child. Talents and life choices of the child might be planned by parents before they were born. A child with higher IQ could be, in the family's eyes, predetermined for a specific role, and failure to achieve such parental expectations might result in family issues (Brenner, D., & Brutlag, D., 2013). Others are concerned about the negative implications of “playing God”, which suggests that selecting against disability is an act of interfering with nature (Macklin, R., 2010). The counterargument here is that PGD is not more a disruption of nature than most of modern age medicine, where efforts to cure disease and to prolong life expectancy are not considered inappropriate. However, Ruth Macklin in 2010 in an article in the journal of Reproductive Medicine supporting social sex selection for family balancing, questioned who should have the power to regulate such advancements in medicine: the government, professional associations, or parents?

Laws

Some countries have laws that prevent or discourage social sex selection. Medical sex selection in the UK is regulated by the HFEA, which has specific guidelines on the genetic conditions for which PGD is permitted. Clinics in the UK are licensed by the HFEA in order to perform PGD (Strange, H., & Chadwick, R., 2010). Non-medical use of PGD for sex selection is illegal in most European countries, including the UK, as well as Canada and Australia. However, there have been reports of couples traveling overseas to seek such services (Macklin, R., 2010; Strange, H., & Chadwick, R., 2010).

In the United States, the American Society for Reproductive Medicine (ASRM) has made recommendations regarding non-medical use of PDG for sex selection. Their ethics committee released a statement in 2001 (restated in 2011) saying “the use of preconception sex selection by pre-implantation genetic diagnosis for non-medical reasons is ethically problematic and should be discouraged”, but “if prefertilization techniques, particularly flow cytometry for sperm sorting, were demonstrated to be safe and efficacious, these techniques would be ethically permissible for family balancing. Because a pre-implantation genetic diagnosis is physically more burdensome and necessarily involves the destruction and discarding of embryos, it was not considered similarly permissible for family balancing”.

The Programme of Action adopted by the United Nations International Conference on Population and Development stands against any use of sex selection techniques for any non-medical reason, and The United Nations strongly recommend all nations "to take

necessary measures to prevent . . . prenatal sex selection.”

In 2002, health workers in China were banned from telling parents the sex of their child. Recently, China ordered a ban on taking blood samples of pregnant women overseas. It had been found that medical organizations were taking blood samples to laboratories out of the country to test for the sex of the baby (Guo, Kai, 2015). The authorities in China appear to be taking action to address their population imbalance issue; how stringently this will be enforced remains to be seen.

Previous Studies

Several studies have attempted to gather information on the views of healthcare professionals regarding social sex selection. A study in 1992 investigated the views of 34 genetic counselors in the United States regarding fetal sex identification and selective abortion, and found that an overwhelming majority of them supported the women’s right to early termination, while objecting to prenatal diagnosis for sex selection purposes (Burke, B. M., 1994). Another survey done in 1998 in an international population looked at 2903 geneticists’ views on prenatal sex selection (Wilton, L., 2009). Almost half (47%) of the respondents reported receiving open requests for social sex selection, and half suspected social sex selection to be a reason for termination although not explicitly revealed. Given a scenario of a family with 4 girls wanting a boy, and willing to terminate the pregnancy if another girl was conceived, 29% reported that they would perform prenatal diagnosis, and 38% reported that they would offer them referrals. Four other scenarios were also studied. In each case, the number given in parentheses

represents the percentage of geneticists who reported that they would perform prenatal diagnosis in that situation: 1. Single woman wants a girl (35%); 2. Poor couple with five boys want a girl (38%); 3. Non-western couple wants a boy (38%); 4. Couple in 40s wants a girl (57%).

A 2006 study by a graduate student at the Sarah Lawrence College Human Genetics Program examined the views of genetic counselors on sex selection for non-medical purposes (McGuire, M., 2006). A survey was conducted through the NSGC membership listserv and had 240 respondents. A majority (71.5%) objected to the use of ultrasound, CVS, or amniocentesis technology for social sex selection, while 45% accepted the use of PGD, and 68.7% accepted the use of Microsort® for social sex selection purposes. Religion had an influence on the genetic counselors' acceptance of PGD and sperm sorting technologies. It was also found that the older respondents, and those who had children, were more accepting of the use of ultrasound, CVS, or amniocentesis for social sex selection.

This study looks at the views of genetic counselors on the issue of pre-conception social sex selection using PGD. Genetic Counselors, especially those working in the preconception specialty, may be the first health care provider that a patient has contact with regarding PGD services. This study looks at how often genetic counselors are faced with these situations at this time, and how they feel about counseling patients interested in social sex selection.

Methods

A survey was sent by National Society of Genetic Counselors (NSGC) eblast and distributed to its members. The survey was created through the online website survey monkey and approved by the Andrus Institutional Review Board on January 7, 2015. Participants answered the survey on a voluntary basis and anonymously. The survey was available from January 28, 2015 to February 18, 2015.

The survey contains 15 questions and took approximately 15 minutes to complete. A 5-point Likert scale was used to collect for responses on questions regarding the views of genetic counselors toward different prenatal tests and procedures to terminate a pregnancy for social sex selection reasons, the potential fears they might have towards social sex selection, and their comfort level in counseling patients seeking social sex selection in different scenarios. Demographic information was collected regarding age, ethnicity, years of experience practicing in the genetic counseling field, and areas of expertise. The data was analyzed using SPSS.

Results

The initial invitation email was sent to 3209 NSGC members with 244 responses, yielding a response rate of 7.6%. The reminder invitation email was sent to 3236 NSGC members with 98 responses, yielding a response rate of 3.0%. In total, 342 responses were received, yielding a response rate of 11%. Fifty six participants provided additional comments.

Table 1. Patient Contact for Social Sex Selection

Have you ever had patients ask you about sex selection?		
Answer Options	Response Percent	n=
Yes	54.1%	125
No	47.6%	110

Chart 1. Frequency of Patient Contact

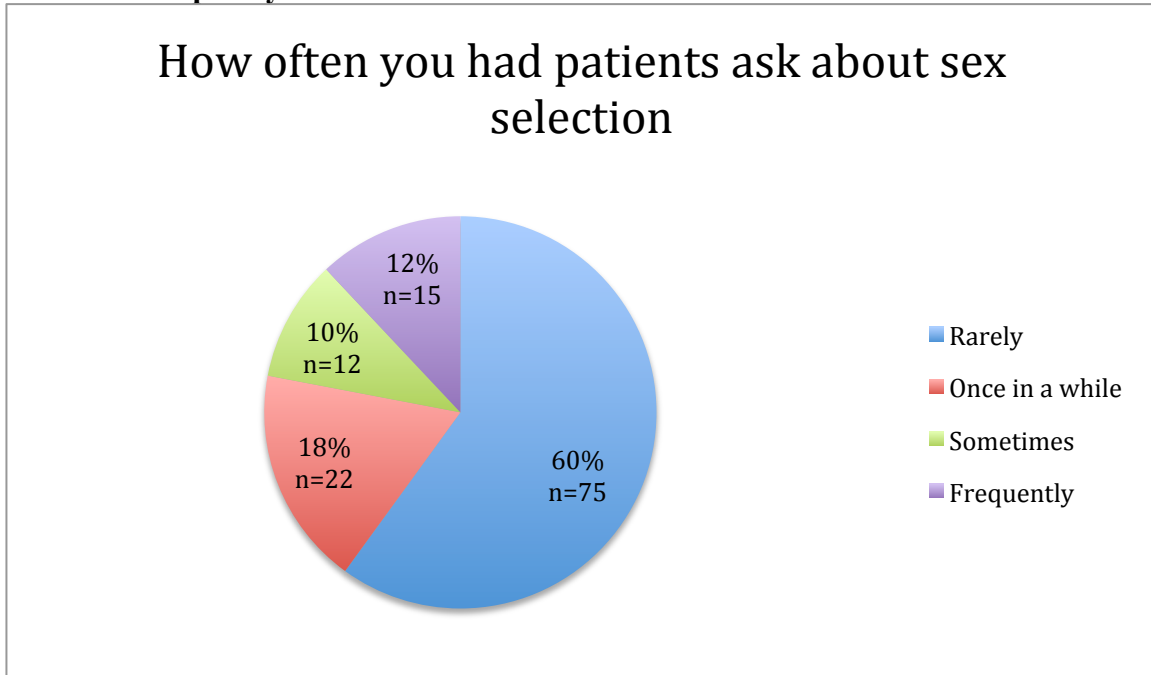


Chart 2. Patient Demographic Information

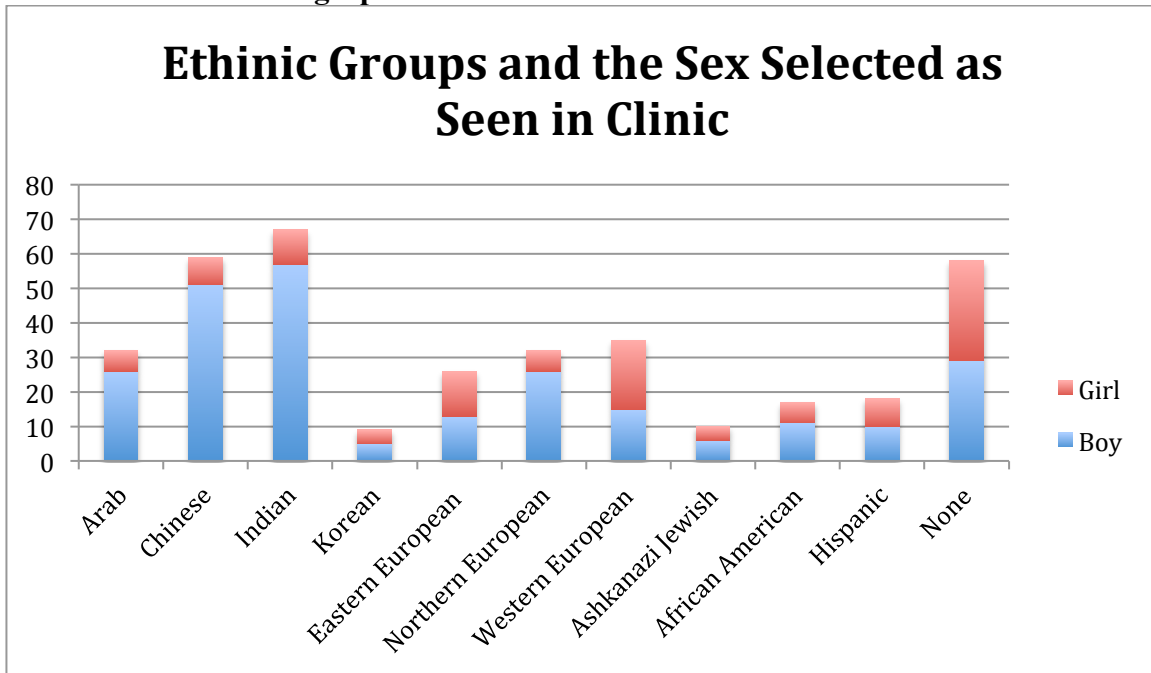


Table 2. Opinion on Pregnancy Termination

For the following statements, choose “Strongly Agree”, “ Agree”, “Neutral”, “Disagree”, or “Strongly Disagree”.							
Answer Options	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	*Rating Average	Response Count
Terminating a pregnancy following amniocentesis or CVS for purposes of sex selection is acceptable.	1.9% (n=4)	4.8% (n=10)	17% (n=37)	37% (n=79)	38% (n=81)	1.9	211
A mother or couple has the right to terminate a pregnancy for sex selection following an amniocentesis or CVS.	15% (n=31)	49% (n=103)	19% (n=41)	5.7% (n=12)	11% (n=24)	3.5	211
Terminating a pregnancy following non-invasive prenatal testing in the first trimester for the purpose of sex selection is acceptable.	1.4% (n=3)	4.2% (n=9)	14% (n=30)	34% (n=72)	46% (n=97)	1.8	211
A mother or couple has the right to terminate a pregnancy for sex selection following non-invasive prenatal testing in the first trimester.	14% (n=30)	42% (n=88)	17% (n=36)	12% (n=25)	15% (n=32)	3.3	211
Using PGD to choose embryos for purposes of sex selection is acceptable.	3.8% (n=8)	24% (n=51)	28% (n=59)	24% (n=50)	20% (n=41)	2.7	209
A mother or couple has the right to use PGD to choose embryos for the purpose of sex selection.	17% (n=31)	46% (n=98)	22% (n=46)	9.5% (n=20)	7.6% (n=16)	3.5	211
Sex selection to prevent X-linked disease is a good use of PGD.	59% (n=123)	36% (n=75)	3.8% (n=8)	1.4% (n=3)	0.48% (n=1)	4.5	210
Sex selection for family balancing is a good use of PGD.	1.9% (n=4)	9.0% (n=19)	26% (n=55)	34% (n=71)	29% (n=62)	2.2	211
Sex selection to provide a first child of a specific sex is a good use of PGD.	1.4% (n=3)	4.3% (n=9)	20% (n=42)	37% (n=79)	37% (n=78)	2.0	211

* (1=Strongly Disagree, 2= Disagree, 3=Neutral 4=Agree, 5=Strongly Agree)

Table 3. Possible Concerns Regarding Social Sex Selection

Which of the following issues affects how you view sex selection? (Check all that apply):		
Answer Options	Response Percent	n=
Sex selection reflects prejudice against women in the US/Canada	26%	53
Sex selection reflects prejudice against women in other cultures	63%	127
Parents should not be able to use technology to choose traits	47%	95
Sex selection might lead to other, more offensive types of trait selection	70%	142
Sex selection may create a male-female population imbalance in other countries	53%	108
Sex selection may create a male-female population imbalance in the US/Canada	25%	51
I don't have any opposition to social sex selection	8.9%	18
Total Response		203

Table 4. Concerns Regarding Social Sex Selection

Which of these is the most important issue?		
Answer Options	Response Percent	n=
Sex selection reflects prejudice against women in the US/Canada	3%	6
Sex selection reflects prejudice against women in other cultures	19%	37
Parents should not be able to use technology to choose traits	26%	52
Sex selection might lead to other, more offensive types of trait selection	36%	72
Sex selection may create a male-female population imbalance in other countries	7.0%	14
Sex selection may create a male-female population imbalance in the US/Canada	1%	2
I don't have any opposition to social sex selection	8.0%	16
Total Response		199

Table 5. Views on Future Use of PGD

Do you have any fears about potential downstream negative effects of allowing sex selection using PGD?		
Answer Options	Response Percent	Response Count
Yes, I am very worried	14%	28
Yes, I am somewhat worried	50%	102
I am not sure	24%	49
No, I am somewhat comfortable	9%	19
No, I am comfortable	3%	7
Total Response		205

Table 6. Concern about Trait Selection

I believe the use of reproductive technology to select traits is likely to become more commonplace over time.		
Answer Options	Response Percent	Response Count
True	72%	148
False	28%	57
Total Response		205

Table 7. Potential Factors Affecting Patient Contact

Answer Options	No problem	Comfortable	Somewhat comfortable	Not comfortable	Would not counsel	*Rating Average
A 50-year-old European couple wanting a firstborn son.	6.4% (n=13)	13% (n=26)	26% (n=53)	42% (n=84)	13% (n=26)	3.4
A 50-year-old Asian couple wanting a firstborn son.	6.4% (n=13)	13% (n=26)	27% (n=54)	41% (n=83)	13% (n=26)	3.4
A 50-year-old couple wanting a firstborn daughter.	6.4% (n=13)	13% (n=27)	26% (n=53)	41% (n=83)	13% (n=26)	3.4
A 25-year-old European couple wanting a firstborn son.	6.4% (n=13)	14% (n=28)	25% (n=51)	41% (n=82)	14% (n=28)	3.4
A 25-year-old Asian couple wanting a firstborn son.	6.4% (n=13)	14% (n=28)	25% (n=50)	41% (n=83)	14% (n=28)	3.4
A 25-year-old couple wanting a firstborn daughter.	6.4% (n=13)	14% (n=29)	26% (n=52)	40% (n=80)	14% (n=28)	3.4
A single woman wanting a firstborn son.	6.4% (n=13)	14% (n=29)	26% (n=52)	40% (n=81)	13% (n=27)	3.4
Total Response						202

* (1=no problem, 2= comfortable, 3=somewhat comfortable 4=not comfortable, 5=would not counsel)

Discussion

The results from our survey suggest that there is an increase in the number of patients seeking social sex selection since 2006. In a 2006 survey of the NSGC membership, 4% of the respondents said they saw patients seeking genetic counseling services requesting social sex selection either “sometimes” or “frequently”. In the current study, 22% of respondents (Chart 1) reported seeing patients seeking social sex selection either “sometimes” (10%, n=12) or “frequently” (12%, n=15). This suggests about a five-time increase in the number of patients seeking this service from genetic counselors.

As the literature predicts, culture and ethnicity were factors impacting who was seeking to use PGD for sex selection and their preferred sex. When asked to describe the scenarios they had encountered, counselors were most likely to report seeing Indian (n=67) or Chinese (n=59) patients requesting sex selection (Chart 2). The data also suggests that this group of patients were more likely to select for boys. They reported seeing more than five times as many requests for selection in favor of boys than girls in these two groups, while, for example, Northern European’s requests were not uncommon (n=52) but sex preferences were evenly split. Several additional comments in this section suggests that European couples were seeking social sex selection services for family balancing reasons, which stands in contrast to the sex-biased preferences reflected elsewhere.

Results of the study suggest that a majority of genetic counselors do not agree with using prenatal medical tests and procedures for social sex selection (Table 2). Most

respondents disagreed or strongly disagreed with the statement “sex selection for family balancing is a good use of PGD” (63%, n=133) and disagreed or strongly disagreed with the statement “Sex selection to provide a first child of a specific sex is a good use of PGD” (74%, n=157). Counselors were somewhat sensitive to issues of timing, and far more respondents agreed or strongly agreed that using PGD to select for embryos to choose sex was acceptable (27.8%, n=59) than agreed or strongly agreed that termination following amniocentesis or CVS for purposes of sex selection was acceptable (6.7%, n=12). Overall, responses suggest that the respondents were uncomfortable with the idea of sex selection at any point before or during pregnancy.

Despite this, a majority of genetic counselors voiced support for the right of patients to terminate a pregnancy for sex selection reasons. Respondents supported the right of a patient to terminate a pregnancy for social sex selection, independent of the prenatal test or procedure used to obtain the information on the sex of the baby. Over half of the respondents agreed with the statement “a mother or couple has the right to terminate a pregnancy for sex selection following an amniocentesis or CVS” (64%, n=134), and the statement “a mother or couple has the right to use PGD to choose embryos for the purpose of sex selection” (61%, n=129). Overall, respondents were supportive of all statements about a woman’s and couple’s right to make any of these choices, even when they had not rated them as acceptable or a good use of the testing. This likely indicates a strong support for abortion rights, and the right to terminate a pregnancy for any reason. Comments like these by respondents supported this interpretation:

“I fully support the right to reproductive choice in our country even when it goes against my personal values. So, while I wouldn't want to be complicit in sex selection, I would still support their right.”

“I don't think anybody likes the idea of terminating a healthy pregnancy, but individuals have the right to terminate a pregnancy up to certain time points for any reason.”

“In the long run, although I don't think sex selection SHOULD be practiced, a couple can choose to terminate a pregnancy for ANY reason, or no reason at all. It is not up to my judgment to put limitations on that right or to be judgmental about their culture.”

Responses to questions that specifically mentioned non-invasive prenatal screening (NIPS) showed a small but consistent increased concern about the use of that procedure for purposes of sex selection as compared to later procedures, which is counter-intuitive. Participants responded negatively to a statement that it was “acceptable” to terminate for sex selection purposes after amniocentesis or CVS (average score 1.9) but even more negatively to an identically worded statement about NIPS (average score 1.8), and more respondents ‘strongly disagreed’ with the statement about NIPS (46%, n=97) than strongly disagreed with the statement about amniocentesis or CVS (38%, n=81). Again, a slightly smaller number of respondents agreed or strongly agreed to the statement “a mother or couple has the right to terminate a pregnancy for sex selection following non-invasive testing in the first trimester” (56%, n=118) than agreed or strongly agreed to the statements “a mother or couple has the right to use PGD to choose embryos for the

purpose of sex selection” (61%, n=129), or “a mother or couple has the right to terminate a pregnancy for sex selection following amniocentesis or CVS” (63%, n=134). This result was unexpected considering the timing of the procedures, since NIPS is the earlier prenatal test. While the differences are small, it may suggest that the respondents were concerned about the potential eugenic implications of the newer procedure in providing information about the sex of the baby in the first trimester.

Respondents were unambivalent about the use of PGD for medical purposes. Genetic counselors approved medical uses by a wide margin: 95% (n=198) of the respondents agreed or strongly agreed with the statement “sex selection to prevent x-linked disease is a good use of PGD”.

A majority of genetic counselors (64%, n=130) expressed that they were either “somewhat worried” or “very worried” about the downstream implications of sex selection (Table 5). Most (72%, n=148) believed the practice would become more common over time (Table 6). Specific concerns varied, and included sexism towards women, creating a population imbalance, and a range of ‘slippery slope’ issues (Table 3).

Counselors showed the greatest concern about the potential that sex selection could be a ‘slippery slope’ issue (Table 4). When asked to indicate which of a list of concerns affected how they viewed sex selection, 70% of respondents (n=142) indicated that it “could lead to other, more offensive forms of trait selection” (Table 3), an increase over the 2006 study where 54% of respondents either “strongly agreed” or “agreed” with the

statement “I am concerned that gender selection will serve as the ‘slippery slope’ for selecting for other non medical traits such as intelligence and athletic ability”. In addition, 47% of respondents (n=95) expressed a related concern that “parents should not be able to use technology to choose traits”. When asked what concerned them the most, 36% (n=72) chose trait selection and 26% (n=52) pointed to parents choosing traits (Table 4). Combined, these responses suggest that respondents were extremely concerned about the implications of being able to use PGD for non-medical purposes as use of the technology increases.

A significant number of genetic counselors expressed concerns about sexism, but it was not their primary concern related to sex selection. A majority of respondents (63%, n=127) included “sex selection reflects prejudice against women in other cultures” when asked to indicate which of a list of concerns affected how they viewed sex selection, and 26% (n=53) included “sex selection reflects prejudice against women in the US/Canada” (Table 3). This response suggests that genetic counselors are aware of and concerned about the issue of sex selection in cultures that favor boys, and where selection against girls has resulted in population imbalances, however, when asked to indicate which one of the same list of concerns they felt was the most important, only a minority of respondents chose sexism against women in other cultures (19%, n=37), and even fewer chose sexism against women in the US and Canada (3.0%, n=6) (Table 4).

A series of questions were designed to investigate the comfort level of genetic counselors with different scenarios involving social sex selection, in order to investigate

the degree to which the motivation and ethnicity of patients would be factors that would affect the behavior or thinking of genetic counselors (Table 7). Scenarios varied as to the age, ethnicity and marital status of the patients, as well as the number and sex of existing siblings. Respondents described their comfort level in all scenarios as somewhere in between “somewhat uncomfortable” and “not comfortable” in every scenario, indicating that they are uneasy with the use of social sex selection, and that this uneasiness is not a function of circumstances.

Conclusion

Preimplantation genetic diagnosis (PGD) started as a medical procedure to select for embryos at risk of X-linked diseases, however, use to select for the sex of the embryos for non-medical reasons is increasing. This emerging use has stirred ethical debates regarding sexism, population imbalance, gender stereotyping, legal issues, and the fear of a slippery slope toward the use of genetic testing for trait selection more generally.

Overall, this study suggests that genetic counselors do not support or approve of the use of PGD for social sex selection purposes, regardless of the type of testing used or the point at which selection occurs. Their biggest concern regarding the use of PGD for sex selection is the concern that it will lead to an increased use of PGD for trait selection in general. Meanwhile, conflictingly, genetic counselors show a strong belief in the right of all patients to terminate a pregnancy even for purposes of social sex selection. The field of genetic counseling may wish to consider how uses of PGD like sex selection can be discouraged without creating policies that limit the rights of women and couples to reproductive rights including termination.

References

1. Blaszczyk, A., Tang, Y. X., Dietz, H. C., Adler, A., Berkeley, A. S., Krey, L. C., & Grifo, J. A. (1998). Preimplantation genetic diagnosis of human embryos for Marfan's syndrome. *Journal of assisted reproduction and genetics*, 15(5), 281-284.
2. Botkin, J. R. (1998). Ethical issues and practical problems in preimplantation genetic diagnosis. *The Journal of Law, Medicine & Ethics*, 26(1), 17-28.
3. Brenner, D., & Brutlag, D. (2013). Eugenics: The Pathway to a Brighter Future or a Slippery Slope of Immorality?.
4. Burke, B. M. (1992). Genetic counselor attitudes towards fetal sex identification and selective abortion. *Social Science & Medicine*, 34(11), 1263-1269.
5. Cecilia Lai-wan, C., Eric, B., & Celia Hoi-yan, C. (2006). Attitudes to and practices regarding sex selection in China. *Prenatal diagnosis*, 26(7), 610-613.
6. Chen, Y., Li, H., & Meng, L. (2013). Prenatal Sex Selection and Missing Girls in China: Evidence from the Diffusion of Diagnostic Ultrasound. *Journal of Human Resources*, 48(1), 36-70.
7. Choe, M. K., & Han, S. H. (1994). Family size ideal and reproductive behaviour in South Korea. In *IUSSP Workshop on Abortion, Infanticide and Neglect in the Asian Past, Kyoto, Japan*.
8. Chun, H., & Das Gupta, M. (2009, April). Gender discrimination in sex selective abortions and its transition in South Korea. In *Women's Studies International Forum* (Vol. 32, No. 2, pp. 89-97). Pergamon.
9. Dahl, E. (2011). FDA bans gender selection procedure. *Institute for Ethics and Emerging Technologies*.
10. Das Gupta, M., Zhenghua, J., Bohua, L., Zhenming, X., Chung, W., & Hwa-Ok, B. (2003). Why is son preference so persistent in East and South Asia? A cross-country study of China, India and the Republic of Korea. *The Journal of Development Studies*, 40(2), 153-187.
11. Delhanty, J. D. (1994). Preimplantation diagnosis. *Prenatal diagnosis*, 14(13), 1217-1227.
12. El-Toukhy, T., Williams, C., & Braude, P. (2008). The ethics of preimplantation genetic diagnosis. *The Obstetrician & Gynaecologist*, 10(1), 49-54.

13. Evans, M. I., Drugan, A., Bottoms, S. F., Platt, L. D., Rodeck, C. A., Hansmann, M., & Fletcher, J. C. (1991). Attitudes on the ethics of abortion, sex selection, and selective pregnancy termination among health care professionals, ethicists, and clergy likely to encounter such situations. *American journal of obstetrics and gynecology*, 164(4), 1092-1099.
14. Fasouliotis, S. J., & Schenker, J. G. (1998). Preimplantation genetic diagnosis principles and ethics. *Human Reproduction*, 13(8), 2238-2245.
15. George, S. M. (2006). Millions of missing girls: from fetal sexing to high technology sex selection in India. *Prenatal diagnosis*, 26(7), 604-609
16. Goodkind, D. (1999). Should prenatal sex selection be restricted? Ethical questions and their implications for research and policy. *Population Studies*, 53(1), 49-61.
17. Greenhalgh, S. (2013). Patriarchal Demographics? China's Sex Ratio Reconsidered. *Population and development review*, 38(s1), 130-149.
18. Guo, Kai. "Gov't Orders End to Sending Blood Samples Abroad for Fetus Sex Checks." *Caixin Online*. Caixin Media Company Ltd., 23 Jan. 2015. Web. 28 Feb. 2015.
19. Han, G., & Yoon, S. E. (2004). The Bilateralization of the kinship Relation in Korean Families: Focused on the Intergenerational Exchange. *Korean Journal of Population Association*, 27(2), 117-203.
20. Handyside, A. H. (1998). Clinical evaluation of preimplantation genetic diagnosis. *Prenatal diagnosis*, 18(13), 1345-1348
21. Hudson, K. L. (2006). Preimplantation genetic diagnosis: public policy and public attitudes. *Fertility and sterility*, 85(6), 1638-1645.
22. Jha, P., Kesler, M. A., Kumar, R., Ram, F., Ram, U., Aleksandrowicz, L., ... & Banthia, J. K. (2011). Trends in selective abortions of girls in India: analysis of nationally representative birth histories from 1990 to 2005 and census data from 1991 to 2011. *The Lancet*, 377(9781), 1921-1928.
23. Kim, D. S. (2004). Missing girls in South Korea: trends, levels and regional variations. *Population (english edition)*, 59(6), 865-878.
24. Kim, D. S., Park, K. S., & Lee, S. Y. (2000). Generational relationship of the middle aged to the elderly parents and their attitudes on old-age security. *Korean Journal of Population Association*, 23(1), 55-90.
25. Li SZ, Yan SH (2008) A special study on the “Care for Girls” campaign. *Popul*

- Family Planning 10:23–24 (in Chinese).
26. Junhong, C. (2001). Prenatal sex determination and sex-selective abortion in rural central China. *Population and Development Review*, 27(2), 259-281.
 27. Macer, D. (2009). Efforts to Overcome Sex Selection in Reproduction in Asia. *Journal of International Biotechnology Law*, 6(3), 122-132.
 28. Macklin, R. (2010, July). The ethics of sex selection and family balancing. In *Seminars in reproductive medicine* (Vol. 28, No. 04, pp. 315-321). © Thieme Medical Publishers.
 29. Malpani, A., & Malpani, A. (2002). Preimplantation genetic diagnosis for gender selection for family balancing: a view from India. *Reproductive biomedicine online*, 4(1), 7-9.
 30. Matken, R., Karabinus, D. S., Harton, G. L., Stern, H. J., Wiley, S., & Blauer, K. L. (2003). MicroSort separation of X and Y chromosome-bearing sperm: ongoing clinical trial results. *Obstetrics & Gynecology*, 101(4), 26S.
 31. McGuire, M. (2006). *Gender Selection for Non-medical Purposes: Genetic Counselors' Viewpoints on how Evolving Medical Technology Will Impact the Genetic Counseling Profession* (Doctoral dissertation, Sarah Lawrence College).
 32. Meseguer, M., Garrido, N., Remohí, J., Simón, C., & Pellicer, A. (2002). Gender selection: Ethical, scientific, legal, and practical issues. *Journal of assisted reproduction and genetics*, 19(9), 443-446.
 33. Murphy, T. F. (2012). Selecting the Traits of Children Prior to Birth. *Virtual Mentor*, 14(2), 158.
 34. Nie, J. B. (2011). Non-medical sex-selective abortion in China: ethical and public policy issues in the context of 40 million missing females. *British medical bulletin*, ldr015.
 35. Park, K. S. (2006). Family and work ties of the Korean elderly. *Population and Society*, 2(1), 89-114.
 36. Pennings, G. (1996). Ethics of sex selection for family balancing: family balancing as a morally acceptable application of sex selection. *Human Reproduction*, 11(11), 2339-2345.
 37. Requirements and Recommendations. (n.d.). Retrieved September 6, 2014, from http://www.microsort.com/?page_id=281

38. Robertson, J. A. (2003). Extending preimplantation genetic diagnosis: the ethical debate Ethical issues in new uses of preimplantation genetic diagnosis. *Human Reproduction*, 18(3), 465-471.
39. Robertson, J. A. (2001). Preconception gender selection. *The American Journal of Bioethics*, 1(1), 2-9.
40. Saurabh, S., Kar, S. S., & Pandey, D. K. (2012). SEX-SELECTIVE ABORTIONS IN INDIA: A BEHAVIOURAL EPIDEMIC. *Indian Journal of Community Health*, 24(1), 67-68.
41. Savell, K. (2012). *Perfecting pregnancy: Law, disability, and the future of reproduction*. Cambridge University Press.
42. Schenker, J. G. (2002). Gender selection: cultural and religious perspectives. *Journal of assisted reproduction and genetics*, 19(9), 400-410.
43. Sermon, K., Van Steirteghem, A., & Liebaers, I. (2004). Preimplantation genetic diagnosis. *The Lancet*, 363(9421), 1633-1641.
44. Sherbahn, R. (n.d.). PGD and IVF Costs - What is the cost for preimplantation genetic diagnosis and/or PGS? Retrieved September 28, 2014.
45. Simpson, J. L. (2010). Preimplantation genetic diagnosis at 20 years. *Prenatal diagnosis*, 30(7), 682-695.
46. Strange, H., & Chadwick, R. (2010). The ethics of nonmedical sex selection. *Health Care Analysis*, 18(3), 252-266.
47. Tizzard, J. (2004). Sex selection, child welfare and risk: A critique of the HFEA's recommendations on sex selection. *Health Care Analysis*, 12(1), 61-68.
48. Verlinsky, Y., Cohen, J., Munne, S., Gianaroli, L., Simpson, J. L., Ferraretti, A. P., & Kuliev, A. (2004). Over a decade of experience with preimplantation genetic diagnosis: a multicenter report. *Fertility and sterility*, 82(2), 292-294.
49. Wertz, D. C., & Fletcher, J. C. (1998). Ethical and social issues in prenatal sex selection: a survey of geneticists in 37 nations. *Social Science & Medicine*, 46(2), 255-273.
50. Wilton, L., Thornhill, A., Traeger-Synodinos, J., Sermon, K. D., & Harper, J. C. (2009). The causes of misdiagnosis and adverse outcomes in PGD. *Human Reproduction*, 24(5), 1221-1228.

51. Zhou, C., Wang, X. L., Zhou, X. D., & Hesketh, T. (2012). Son preference and sex-selective abortion in China: informing policy options. *International journal of public health*, 57(3), 459-465.