Attitudes about preconception sex selection: a focus group study with Americans

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BACKGROUND: MicroSort, a sperm-sorting technology for sex selection, may eventually be approved by the Food and Drug Administration and marketed to the public. Data on US public attitudes about the morally appropriate uses and regulation of this technology are lacking. METHODS: We conducted 20 focus groups in April 2003 with participants from five major US cities to identify the values that shape Americans' attitudes about the use and regulation of preconception sex selection (PSS) technology. One hundred and seventy-six individuals between the ages of 18 and 68 were assigned to groups ranging from 6 to 11 participants based on their location, sex, race/ethnicity, religion, age, education and parental status. Qualitative analysis of focus group transcripts was conducted using NVivo 2.0 software to determine beliefs and values that shape participants' opinions about the appropriate use and regulation of PSS. RESULTS: Most participants strongly favor using PSS to avoid X-linked genetic diseases. Although some participants were uncomfortable with the use of PSS for non-medical sex selection, believing it to be 'selfish' and inconsistent with parental love, they did not perceive the potential harms to be significant enough to warrant governmental intrusion into reproductive decisions. CONCLUSIONS: PSS should face little public opposition in the US if widely marketed.

Keywords: sperm sorting; MicroSort; public opinion; attitudes; qualitative research

Introduction

Throughout history, couples have attempted to influence the sex of their children. For instance, the Greeks believed that tying off the left testicle would produce a boy (Confine et al., 2006). Effective modern methods of sex selection, such as prenatal testing followed by intentional miscarriage or preimplantation genetic diagnosis (PGD), require destruction of a fetus or embryos that are not the desired sex and, therefore, are not as attractive to potential consumers as preconception methods (Dixon and Levy, 1985). preconception sperm sorting methods for sex selection have been on the market for decades (Ericsson et al., 1973; Glass, 1977; Hegde et al., 1977; Shastry et al., 1977; Cartwright et al., 1993; Ericsson, 1994; Wang et al., 1994), the validity of the studies and effectiveness of the methods have been questioned (Broer et al., 1978; Zarutskie et al., 1989; Jaffe et al., 1991; Flaherty et al., 1997; Richards et al., 1997).

A newer method of preconception sex selection (PSS) is now available. MicroSortTM uses flow cytometry to separate X- and Y-bearing sperm and is an effective form of PSS for couples who desire a girl (Fugger *et al.*, 1998). MicroSortTM is now widely available for consumers to purchase through clinical trials in 112 collaborating clinics in 31 states throughout the

USA and six additional countries (microsort.com; Weber; Golden, 1998; Belkin, 1999; Kalb, 2004; Grady, 2007). Couples using MicroSortTM to avoid an X-linked genetic disease participate for free.

The use of PSS, particularly for non-medical sex selection, is a divisive ethical issue widely debated in the literature by healthcare providers and bioethicists (Berkowitz, 1999; Sureau, 1999, 2004; McCarthy, 2001; Robertson, 2001; Dahl, 2003, 2004; ACOG Committee on Ethics, 2004; ASRM Ethics Committee, 2004; McDougall, 2005; Milliez, 2007; Purdy, 2007; Blyth *et al.*, 2008). Concerns about the use of PSS include that it will alter the sex ratio of a population, that it is a form of discrimination against women and that it will change the way we think about children.

Public opinion survey data on the use of PSS have explored the potential demand for an effective method of PSS primarily to determine the market potential (Marleau and Saucier, 2002; Jain *et al.*, 2005; Dahl *et al.*, 2006; Hall *et al.*, 2006; Van Balen, 2006) and sex preferences of potential consumers to determine whether the introduction of an effective PSS method would likely alter the sex ratio of a population (Steinbacher and Gilroy, 1985; Khatamee *et al.*, 1989; Walker and Conner, 1993; Liu and Rose, 1995; Marleau and Saucier, 2002;

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Swetkis *et al.* 2002; Zubair *et al.*, 2007; Himmel *et al.*, 2008). However, these studies were not designed to understand public attitudes toward the 'ethics and regulation' of PSS.

Recent studies by Scully et al. (2006a,b) and contracted qualitative and quantitative public consultations conducted for the Human Fertilisation and Embryo Authority (HFEA, 2003, Appendices E and F) have investigated the lay public's beliefs about the ethics and regulation of non-medical sex selection among residents in the UK. A majority of focus group participants in northeast England believed that nonmedical sex selection was ethically unacceptable (Scully et al., 2006b). Deeper analysis of these arguments found that selecting for sex is not consistent with being a good parent because it is selfish and does not treat a child as a gift that is accepted unconditionally. Similarly, findings from the HFEA public consultation found concerns that social sex selection reinforces sexual stereotypes, will lead down a slippery slope to designer children, commodifies children, could result in negative psychological consequences for all children in the family, could result in a sex-ratio imbalance in certain cultures, is not a good use of medical resources and violates God's design. As a result, the vast majority of participants in both the qualitative and quantitative studies conducted throughout the UK found that the public supported existing law that permits sex selection to avoid a genetic disease, but bans it for social sexing (HFEA, 2003, Appendices D and F).

We sought to understand public attitudes of US residents toward the ethics of using this technology to avoid an X-linked disease, for 'family balancing' and for a first-born child. We also explored how participants felt about regulating PSS for these uses. Focus groups were used to allow participants to express their opinions without preconceived categories created by the researchers.

Materials and Methods

Participants

Volunteers of different sex, race/ethnicity, religion, age, education level and parental status were recruited from five different cities to ensure a broad range of responses. Because shared life experience results in more in-depth discussion, participants with similar demographic characteristics were grouped together. Women were intentionally over-represented in the sample because the reproductive technologies discussed in this study involved women's medical care.

The protocol was reviewed by the Johns Hopkins Institutional Review Board and participants gave their informed consent to participate and be audiotaped.

Data collection

Data reported here come from a larger focus group study looking at American attitudes toward the use of reproductive genetic technologies (Kalfoglou *et al.*, 2005). Participants were asked to consider how they might council a 'friend' considering using each of these technologies because this indirectly allowed participant to discuss the ethics of the uses of these technologies. The scenarios involved a 'friend' using carrier testing, PGD, prenatal testing using amniocentesis or chorionic villus sampling, hypothetical genetic modification and PSS for a variety of medical and non-medical purposes. Participants were asked to discuss their attitudes about the use of PSS for

Table I. Scenario progressions.

Scenario 1: sex selection to avoid X-linked genetic disease

Your friend has three brothers who died from Duchenne Muscular

Dystrophy, an X-linked genetic disease

She is a carrie

If she has a boy, there is a 50/50 chance he will have the disease

If she has a girl, there is a 50/50 chance she will be a carrier, but she will not have the disease

A new technique is available that separates sperm in order to increase chances of having a girl

The technique is not 100% accurate (but is over 90% accurate for selecting a girl)

Procedure costs about \$2500 and is not covered by insurance

Scenario 2: sex selection for 'family balancing'

Your friends have no known risk of an X-linked genetic disease

They have three boys and want a girl

Scenario 3: sex selection for first-born child

Your friends have no known risk of an X-linked genetic disease

They do not yet have children

They want only one child and want it to be a boy

The technology is less accurate (75%) when selecting for a boy

three different purposes (Table I). In the first scenario, participants were told that they had a friend who was at risk of having a child with Duchenne Muscular Dystrophy. The hypothetical couple's intent was to use PSS to avoid having a boy since only a boy would be at risk of developing the disease. In the second scenario, participants were asked to react to a situation where friends, who have no known risk of a sex-linked genetic disease, want to use PSS because they have three boys and want a girl. Finally, participants were asked what they thought about a friend wanting to use PSS to ensure their first-born child was a boy. All discussions were led by experienced moderators using a detailed focus group guide.

Data analysis

Focus group discussions were tape recorded, transcribed and entered into the qualitative analysis program NVivo 2.0. Transcripts were read repeatedly by members of the research team to identify themes. Themes were turned into a coding structure, and the text was then coded. Two members of the research team in addition to the authors reviewed the identified themes to ensure they were consistent with the data. Key quotes that exemplified major themes were identified.

Results

In April 2003, 181 individuals in five states were recruited to participate in 21 focus groups on reproductive genetic technologies. PSS was discussed with 176 individuals in 20 focus groups (focus group #3 did not cover this topic and was excluded from this analysis). Six focus groups were conducted in both Massachusetts and California, and three each in Tennessee, Colorado and Michigan. Twelve groups were exclusively female, six exclusively male and three included both genders. The majority of the focus groups were with people of reproductive age; however, two were groups of 18-25-year-olds, and one was exclusively 55 years of age and older. Two groups were exclusively Mexican Americans, four were African-Americans, one was Chinese-Americans, three were Caucasians and the rest were racially mixed. Four groups were exclusively Jewish, Protestant, Evangelical or Catholic women. Three groups were exclusively participants with a high school diploma or less, and two had a college

degree or more education. Focus groups had a range of 6-11 participants per group (mean = 9).

Sex selection to avoid X-linked genetic disease

Within all 20 focus groups, there were expressions that using PSS to avoid a genetic disease was a good use of the technology. When the justifications for this attitude were analyzed, we found four themes. First, the fact that no embryos would be harmed using this technology was cited in 12 of the groups (Table II).

It's not a baby yet, so I can't really say that it is wrong. It's just a personal choice.—woman from Colorado

Second, just over half of the focus groups (11) discussed the fact that this was a reasonably inexpensive way of preventing a genetic disease. Third, the fact that this procedure was non-invasive (compared with IVF or prenatal testing) was discussed in six focus groups. Finally, participants in three focus groups thought that the use of PSS might prevent the intentional miscarriage of an affected fetus.

Participants within eight of the focus groups discussed reasons why they thought using PSS to avoid a genetic disease was ethically unacceptable. The most frequent objection to this use, mentioned in six focus groups, was that selecting sex, even to avoid the birth of an affected child, is a violation of God's will. In other words, if a child is born with a genetic disease, it is part of God's larger plan, and it is hubris to attempt to circumvent that plan.

Table II. Themes by scenario.

Scenario 1: sex selection to avoid X-linked genetic disease

Reasons to use PSS

- 1. No embryos harmed
- 2. Inexpensive way to prevent genetic disease
- 3. Non-invasive
- 4. Might prevent intentional miscarriage

Reasons against using PSS

- 1. Selecting for sex is a violation of God's will
- 2. Female child still has a 50/50 chance of being a carrier
- 3. Accuracy of technology
- 4. Slippery slope to non-medical use

Scenario 2: sex selection for 'family balancing'

Reasons to use PSS

- 1. Lack of harm that would justify limiting access to technology
- 2. No embryos harmed
- 3. Avoid conception of unwanted children
- 4. Avoid sex selection intentional miscarriages

Reasons against using PSS

- 1. It is selfish and will lead to the commodification of children
- 2. It will lead to a population imbalance
- 3. Unnatural/goes against God's will
- 4. Only wealthy can afford it
- 5. Gender confusion for child who 'should have been other sex'
- 6. Increase gender discrimination
- 7. Psychological harm for child born the undesired sex

Scenario 3: sex selection for first-born child

Reasons against using PSS:

- 1. Population imbalance (but probably not a problem in U.S.A.) Regulation
 - 1. No government regulation
 - a. Will lead to erosion of reproductive rights
 - 2. Prevent non-medical sex selection
 - a. Physicians should limit access
 - b. Government should limit use

I'm sorry, where is the miracle of life? I just think people are just taking away too much of God.—woman from Tennessee

Similarly, within two focus groups, concern was expressed regarding the loss of a child that was meant to be but was never conceived.

It's not really the same as preventing a cold...so if they had chosen to have a boy instead [of a girl]...that is preventing a life.—woman from Colorado

Among those who thought it was acceptable to use PSS to avoid genetic disease in at least some cases, three concerns emerged. First, participants in 10 different groups mentioned that female children would still have a 50% chance of being a carrier of the disease. They argued that this will just pass the burden of the disease to the next generation.

If they do go on to have a girl, then she turns out she is a carrier, then she is faced with this decision down the road also. They are basically passing the problem on to her.—man from Tennessee

Other groups mentioned that by leaving open the possibility of creating a carrier daughter, the couple was still at risk of being burdened by a child with the disease because they might have to parent their grandchild. Second, participants in eight focus groups were concerned about the accuracy of sperm sorting. They felt that the risk of the disease was so great that more invasive, but more accurate technologies such as PGD or prenatal testing were better alternatives. Finally, participants in eight focus groups were concerned that development of PSS for medical sex selection would inevitably lead to the use of the technology for non-medical purposes.

Sex selection for 'family balancing'

Participants had very mixed responses to the 'family balancing' scenario. Discussions, where PSS for this purpose were perceived to be ethically acceptable, were typically framed in terms of a perceived lack of harm that would justify interfering with someone's reproductive rights. For instance, eight focus groups brought up that couples ought to have the freedom to make their own decisions regarding the use of reproductive technologies.

Hey, this is America. You should be able to do what you want.—woman from Colorado.

The fact that no embryos are harmed using this technology was a salient point to justify the use of PSS for non-medical sex selection within seven of the focus groups.

It is pre-fertilization. It isn't (like) a life is even at stake yet.—woman from California

Additionally, focus group participants thought that using sperm sorting for family balancing might avoid greater harms. Within seven focus groups, participants thought that avoiding the conception of children that are an undesired sex was a good outcome of the technology.

[H]ow much are the other children going to suffer because now they have five kids before they got a boy?—man from Massachusetts Finally, members of two focus groups thought that using PSS might help to avoid intentional miscarriages.

Better for them to allow people to spend \$2500 to determine the sex of their baby ahead of time than actually have them get pregnant and now you legally can decide whether or not to abort that child.—woman from Massachusetts

Moral objections to non-medical PSS fell into three primary themes. First, participants were concerned that couples using it for this purpose were being 'selfish' and were not accepting what life brings. This theme was prominent and was discussed in 18 of the 20 focus groups.

[Y]ou can't map out exactly the way your family will look and be You've got to be open minded and accept what you get.—man from Tennessee

Within this theme was concern that the ability to choose the sex of your child will lead to commodification of children.

It almost turns into like shopping or something, you know? Okay, I want a boy that's about 6'4', muscular, blonde hair, blue eyes, very smart...it's like almost something you do on the computer and a kid pops out and it really takes out the human element.—man from Colorado

A second objection to the use of PSS for non-medical reasons, mentioned in half of the focus groups, was the concern that this could lead to a population imbalance.

[I]t just takes away the whole natural selection. I mean we'd have a culture that's entirely men and then what does that do?—woman from Colorado

The expectation that males would be favored over females was nearly universal except for one woman from Tennessee who was concerned that females would be chosen over males because of a male propensity toward violence.

A third reason for rejecting non-medical PSS was the idea that selecting the sex of your child for social reasons is unnatural and goes against God's will. This theme was covered by many of the focus groups during the discussion of sex selection to avoid genetic disease, but was specifically raised during the discussion of family balancing in four focus groups.

[I]t feels like we're taking this incredible gift and process of giving birth to a child, and turning it into a scientific process, and that completely goes against what I believe.... I want to know that when I go to have a baby, that, especially we're talking just sex here, I want to leave that up to whatever the Creator decides He wants to give me, and trust that there is a reason that I'm going to have a boy instead of a girl. I don't believe it's just a random chance.—man from Colorado

In addition to the three primary themes discussed above, additional issues regarding non-medical sex selection were raised. Participants in four focus groups expressed concern that only the wealthy would be able to afford to use the technology. Participants in four additional groups were concerned that a child who was 'meant to be' one sex, but was born the other as the results of sperm sorting might experience gender confusion. Uncommon concerns, discussed in two focus groups, included fear that the use of the technology might contribute

to sex discrimination and that children born after an inaccurate sex selection would not be able to live up to parental expectations.

Sex selection for first-born child

When participants were asked to discuss the use of PSS to ensure a first-born child would be male, the only issue discussed was that this use could lead to a sex-ratio imbalance (Table II). The sex-ratio imbalance in China was frequently mentioned.

I would oppose it because what if most of the population in the world, they want boys? Then we'd be totally non-functional.—woman from Massachusetts

However, in five groups where this concern was discussed, at least one person dismissed this concern as not applying to US culture.

Beliefs about regulation

All 20 groups had discussions about the regulation of reproductive genetic technologies; however, the topic naturally emerged in eight of the focus groups as they were discussing the use of PSS. Within these eight discussions, the primary theme related to ensuring that individuals have the freedom to make reproductive decisions unimpeded by the government.

Why would you want somebody else involved?... what about your privacy?... You have to have the permission of the government to do what you want to do with your sperm and egg?—woman from California

At least three women expressed concern that if the government tried to regulate the use of PSS, it could lead to an erosion of reproductive rights, particularly the right to intentional miscarriage.

Many participants were in favor of physicians offering this technology for medical purposes only, but this was not always explicitly stated. Instead, many participants presumed that physicians who would provide non-medical sex selection were unprincipled.

I am sure there's probably couples who would want [non-medical sex selection], and probably doctors with not much ethics who would go ahead and do it.—woman from California.

There were participants within three groups who recognized how difficult it would be to try to limit the use of PSS for a certain purpose, but nonetheless thought there ought to be attempts to prevent the use of PSS for non-medical sex selection through governmental regulation.

Discussion

These focus group participants almost universally agreed that avoiding X-linked genetic diseases was an ethical use of PSS technology. Because this finding is consistent with attitudes of US medical students (Mastroianni, 1999) and members of the lay public in England (Scully *et al.*, 2006a,b), and the UK (HFEA, 2003), we expect that, if approved by the Food and Drug Administration, MicroSortTM will receive strong public support for this limited use.

Compared with other reproductive genetic technologies discussed earlier in the focus groups, participants had a difficult

time articulating why they were uncomfortable with PSS for non-medical reasons—though clearly many objected to it. The fact that PSS was discussed after PGD, which involves the potential destruction of embryos, likely influenced the theme that PSS was not morally objectionable because 'nothing is destroyed'. Discomfort with PSS for non-medical reasons was shaped by participants' beliefs related to interfering with 'nature' or 'God's will', concerns about commodifying children and ideas about proper parental love. The adjective most frequently used by participants to describe those who might use PSS for non-medical sex selection was 'selfish'. They thought couples seeking PSS were not open to accepting whatever child was born. This theme is reminiscent of similar findings by Scully et al. (2006b) among the lay public in the northeast of England in that children ought to be thought of as 'a gift rather a commodity'. In contrast to focus group participants in England, our focus group participants frequently referred to the 'gift' of a child as being from God; however, the conclusion that the 'gift' ought to be accepted unconditionally and with gratitude was the same. Our findings are also consistent with arguments made by experts that non-medical sex selection is inconsistent with parental love (Herissone-Kelly, 2007a,b) and that good parents take the needs of future children into consideration, 'relinquishing control over their children' except to protect them from harm (Scully et al., 2006a). In contrast to the findings from Scully (2006a,b), we found that some focus group participants thought that the use of PSS for social sexing might actually be consistent with good parenting if it would help families to avoid the births of multiple children who were the undesired sex.

Few participants thought that the use of PSS ought to be limited by regulations. Perspectives that stress individual freedom appear to extend to PSS regardless of the purpose for its use. This is in contrast to focus group participants from England and the UK who thought that access to non-medical sex selection ought to be limited by regulations (HFEA, 2003; Scully *et al.*, 2006b). Participants did not state explicitly that using PSS for non-medical sex selection was outside the scope of medicine; however, a theme did emerge that the use of PPS for this purpose would be impossible to control because there would always be physicians willing to provide access to the technology for financial gain.

There are some limitations to this study. During the discussions, PSS was presented as costing \$2500 per insemination. We inadvertently failed to mention that for each insemination, there is only an 18% chance of pregnancy. Had this information been presented, there might have been more expression of a reluctance to personally use this technology because of its cost; however, the lack of consideration of cost should have little effect on attitudes about whether or not different uses of this technology are ethical.

Additionally, the moderators did not discuss the fact that there may be unknown risks to offspring resulting from this procedure. The fact that safety was not raised as an ethical concern should not be interpreted to mean that this is not important to the participants. Safety was an essential component in determining whether or not the use of a technology was ethical in discussions of all the other reproductive

genetic technologies. In the PSS scenarios, participants may simply have presumed that 'sperm sorting' was safe.

On the basis of our findings, there may be some resistance to the use of PSS for non-medical sex selection and stigmatization of physicians who are willing to provide it in the USA on ethical grounds, but it is unlikely to lead to public support for governmental regulation unless PSS leads to measurable changes in the sex ratio. Survey data examining people's preferences for the sex of their children in the Western world suggest that the introduction of PSS is unlikely to upset the sex ratio (Steinbacher and Gilroy, 1985; Khatamee et al., 1989; Walker and Conner, 1993; Liu and Rose, 1995; Swetkis et al., 2002). Additionally, healthcare providers who choose to make MicroSortTM available for non-medical reasons could limit its use to 'family balancing' or monitor and equalize the number of female and male children they help produce in order to address this concern. This practice would be in concert with the recommendations of the Ethics Committee of the American Society for Reproductive Medicine (ASRM, 2004).

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