

Opinions about new reproductive genetic technologies: Hopes and fears for our genetic future

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Objective: To identify underlying beliefs and values shaping Americans' opinions about the appropriate use of new reproductive genetic technologies (RGTs), including preimplantation genetic diagnosis, hypothetical genetic modification, and sperm sorting for sex selection.

Design: Scenarios with ethical dilemmas presented to 21 focus groups organized by sex, race/ethnicity, religion, age, education, and parental status.

Setting: A city in each state: California, Colorado, Massachusetts, Michigan, and Tennessee.

Participant(s): One hundred and eighty-one paid volunteers, ages 18 to 68.

Intervention(s): None.

Main Outcome Measure(s): Beliefs and values that shape participants' opinions about the appropriate use of new RGTs.

Result(s): Regardless of demographic characteristics, focus group participants considered six key factors when determining the appropriateness of using RGTs: [1] whether embryos would be destroyed; [2] the nature of the disease or trait being avoided or sought; [3] technological control over "natural" reproduction; [4] the value of suffering, disability, and difference; [5] the importance of having genetically related children; and [6] the kind of future people desire or fear.

Conclusion(s): Public opinions about the appropriate use of RGTs are shaped by numerous complementary and conflicting values beyond classic abortion arguments. Clinicians and policy-makers have the opportunity to consider these opinions when creating messages and crafting policy. (*Fertil Steril*® 2005;83:1612–21. ©2005 by American Society for Reproductive Medicine.)

Key Words: Focus groups, genetic modification, in vitro fertilization, preimplantation genetic diagnosis, public opinion, qualitative research, reproductive genetics, sex selection

New reproductive genetic technologies (RGTs)—preimplantation genetic diagnosis (PGD), hypothetical genetic modification, and sperm sorting for sex selection—have the potential to avoid human disease and increase parental choices; however, like other advances in reproductive technology, their introduction into medical practice raises important eth-

ical, legal, and social issues. Government ethics advisors have called for new policies to regulate these technologies (1), and some health care providers have argued that decisions about the appropriate use of reproductive technologies are best made between providers and their patients (2, 3).

Several countries have initiated large-scale public consultations to elicit public opinion on the use and regulation of RGTs (4–11). The United Kingdom has conducted public dialogues specifically on PGD (12) and sex selection (13). In the United States, an understanding of public opinions about RGTs comes mainly from survey data. Most surveys, including our own (14, 15), have shown that there is overwhelming public support for the availability of prenatal genetic testing, carrier testing, and new RGTs to avoid disorders like Down syndrome and other conditions that present a serious threat to health (16–20). In contrast, these same studies show little

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support for the hypothetical use of RGTs to select for or alter traits such as intelligence, obesity, or homosexuality.

Public concerns about RGTs include the belief that their use is too much like “playing God,” fear that the technologies will be used for the wrong purposes, unease about the potential for discrimination, and concern about inequitable access to these technologies (14, 15, 21). Religion, race/ethnicity, sex, and age have all been shown to influence beliefs about RGTs (14, 15, 21–23).

A clear understanding of why people hold certain opinions about RGTs is lacking but is vital to inform the policy-making process. The development of policy should consider people’s answers to questions such as: Why is the use of RGTs acceptable in some situations but not in others? What concerns people about the potential uses of RGTs? What do people really mean when they say using RGTs is too much like “playing God”? Surveying the public will fail to answer these types of questions. Answering such questions requires a qualitative approach in which research participants can be asked open-ended questions, be probed to elaborate on responses, and react to scenario changes. We used focus groups, held in different parts of the country, to gain a deeper understanding of diverse opinions.

MATERIALS AND METHODS

Participants

Healthy volunteers of different sex, race/ethnicity, religion, age, education level, and parental status were recruited to ensure a broad range of responses. Because shared life experience results in more in-depth discussions (24), participants with similar demographic characteristics were grouped together (Table 1). Women were intentionally over-represented in the sample because it was assumed that they make the majority of reproductive decisions.

Focus Group Protocol

All study materials, including the informed consent form, were reviewed and approved by the institutional review boards at the Johns Hopkins Medical Institutions, Abt Associates Inc., and the University of Pennsylvania. Potential participants were identified through existing databases provided by a national focus group vendor, contacted by telephone, and asked if they would like to take part in a focus group to discuss “issues related to genetics and having children.” Candidates were then screened to verify that they met the inclusion criteria, and some demographic data were collected. People were eligible to participate if they were fluent in English and had not participated in a focus group within the last 6 months. Individuals were offered \$75 to participate. Participants did not know one another.

Experienced moderators led the focus groups, and, whenever possible, were matched to participants’ characteristics on sex, race/ethnicity, and age. All discussions followed a detailed focus group guide, which was extensively pilot

tested (available at <http://www.DNAPolicy.org>). The focus group guides were identical for each group except that the genetic disease was changed for ethnic relevance. African American, Jewish, and Asian groups discussed sickle cell anemia, Tay-Sachs disease, and thalassemia, respectively. All other mixed race and Caucasian groups discussed cystic fibrosis. After an initial icebreaker question, scenarios involving imaginary friends were presented to participants. Each scenario involved a couple faced with a situation in which they needed to choose whether to use a particular RGT, and participants were asked to provide this couple with advice. Technologies discussed included carrier testing, prenatal testing, PGD, hypothetical genetic modification, and sperm sorting for sex selection (Table 2). Findings related to the use of PGD, hypothetical genetic modification, and sperm sorting for sex selection are reported here.

The scenarios began with the most familiar technologies and progressed to more complex and/or hypothetical technologies. Decision-making scenarios also took participants down the “slippery slope” of ethical dilemmas—beginning with the use of RGTs to avoid serious, potentially fatal disease, then moving on to consider less serious, nonfatal health conditions, and finally to the selection or modification for socially desirable traits. Discussions ended with participants sharing their thoughts on the social and policy implications of these technologies, whether these technologies should be regulated, and if so, by whom.

Co-investigators observed each 2-hour focus group from a soundproof room behind a mirrored window. Groups were video and audio taped to create verbatim written transcripts. All references to personally identifying information were deleted from the transcripts to protect participants’ privacy, but each speaker was tracked throughout the transcript to maintain the context and individual character of the text.

Data Analysis

The coding scheme was developed through a collaborative and iterative process according to the method of McQueen et al. (25) when multiple coders are involved. Co-investigators read the transcripts and discussed factors related to participants’ attitudes about appropriate uses of RGTs that emerged from the data. The codebook was tested several times, reviewed, and revised by the research team until redundancy of factors was achieved. Transcripts were analyzed using the computerized qualitative data analysis package NVivo 2.0 (QSR International, Doncaster, Victoria, Australia). The quality of the coding process was assessed according to standard qualitative research methodologies (26).

Limitations

Our study has a number of limitations. First, our sample included people from urban and suburban areas. Whether individuals from rural communities or states not represented here hold different views on these issues requires further

TABLE 1**Focus group characteristics.**

Group Number	Number of People	Location	Sex	Age (years)	Parent?	Race/Ethnicity	Religion	Education
1	8	Massachusetts	Mixed	25–40	N/A	N/A	N/A	N/A
2	7	Massachusetts	Female	35–45	N/A	N/A	Jewish	N/A
3	5	Massachusetts	Female	25–34	N/A	Mexican American	N/A	N/A
4	7	Massachusetts	Mixed	25–34	N/A	N/A	N/A	N/A
5	9	Massachusetts	Male	25–34	N/A	African American	N/A	N/A
6	6	Massachusetts	Female	25–45	N/A	N/A	Protestant	N/A
7	9	Tennessee	Female	25–34	N/A	African American	N/A	College degree or greater
8	9	Tennessee	Male	35–45	N/A	African American	N/A	N/A
9	8	Tennessee	Male	18–25	No	N/A	N/A	N/A
10	10	California	Female	35–45	No	N/A	N/A	N/A
11	7	California	Female	35–45	N/A	Mexican American	N/A	N/A
12	9	California	Male	35–45	N/A	Mexican American	N/A	N/A
13	9	California	Male	35–45	N/A	N/A	N/A	With/without a high school diploma
14	9	California	Mixed	55+	Yes	N/A	N/A	N/A
15	7	California	Female	25–45	N/A	Chinese American	N/A	N/A
16	11	Colorado	Female	25–34	N/A	N/A	Evangelical	N/A
17	11	Colorado	Female	18–25	No	N/A	N/A	N/A
18	8	Colorado	Male	25–34	N/A	Caucasian	N/A	College degree or greater
19	10	Michigan	Female	35–45	N/A	Caucasian	N/A	With/without a high school diploma
20	11	Michigan	Female	35–45	N/A	African American	N/A	With/without a high school diploma
21	11	Michigan	Female	25–34	N/A	Caucasian	Catholic	N/A

Note: N/A = not applicable.

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TABLE 2**Focus group scenario progression.**

Carrier testing
 Prenatal testing
 Preimplantation genetic diagnosis

- for life-threatening childhood disease
- for adult-onset disease
- for obesity and depression

 Hypothetical genetic modification

- for life-threatening childhood disease
- for adult-onset disease
- for obesity and depression
- for intelligence

 Elective sex selection through sperm sorting

- for genetic disease
- for family balancing
- for firstborn

 Thoughts about the impact on society
 Attitudes about regulation

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study. Second, our sample had a higher level of education than the national average, so participants may have had more preexisting knowledge about these technologies. Third, because the general topic was disclosed to people before they agreed to participate, there was likely self-selection bias. Those most opposed to RGTs may have been underrepresented in this sample.

RESULTS

As presented in Table 1, a total of 181 people participated in 21 focus groups, which were conducted in five U.S. metropolitan areas in California, Colorado, Massachusetts, Michigan, and Tennessee in April 2003. Participants were predominantly female (65%), Caucasian (55%), parents (57%), and ranged in age from 18 to 68. Fifty-seven percent had a college degree or higher. Four groups were made up of women who actively participated in one of each of the following religious traditions: Evangelical, Mainline Protestant, Catholic, and Jewish. African Americans, Latinos, and Asians made up 25%, 16%, and 4% of all participants, respectively. The focus groups had a range of 5 to 11 participants per group (mean = 8.6).

Virtually no participants had heard about PGD, although some participants spontaneously predicted it. There was some awareness of genetic modification, mostly from science fiction. Some participants knew that sex selection techniques exist, but they were likely to talk about “wives’ tales” for increasing the chance of conceiving a boy or a girl.

When participants contemplated whether the use of RGTs is or is not appropriate, they stated that the safety, accuracy, and effectiveness were essential. Assuming these technolo-

gies were safe, accurate, and effective, six additional factors were identified that influenced participants’ beliefs about the appropriate use of RGTs (Table 3). Some factors were more or less pronounced, depending on the technology. Each factor is discussed below, and quotations are included to provide illustration.

Possible Destruction of Embryos

Focus group participants were presented with a scenario in which a couple knew they were at risk of having a child with a genetic disease. The PGD process was described to them, and participants were asked to give the couple advice about whether to use the technology. During the conversations, peoples’ attitudes about the destruction of preimplantation embryos emerged. Among a majority of focus group participants, the loss of preimplantation embryos was perceived to be morally distinct from a second-trimester abortion following prenatal diagnosis because preimplantation embryos are not in the woman’s womb and they are at a much earlier stage of development. Additionally, participants thought there would be less emotional trauma associated with discarding embryos than with aborting a wanted fetus with whom the woman and family had bonded.

I just keep thinking of embryos and implanted embryos. Those are very different things. (*Woman from mixed sex/race group, Massachusetts*)

[PGD] is definitely better than the 4-month situation ... in my mind that’s obviously a true abortion. At 3 days, I don’t see it as that ... I can separate myself emotionally from cells in a dish. (*Participant from Caucasian men’s group, Colorado*)

Most participants who supported the use of PGD still saw value in the embryo, even if it was just the effort expended in its creation. These participants frequently recommended donating “affected” embryos for disease research rather than discarding them.

TABLE 3**Factors participants considered when evaluating the appropriate use of new reproductive genetic technologies.**

1. The possible destruction of embryos
2. The nature of the disease or trait being avoided or sought
3. Technological control over “natural” reproduction
4. The value of suffering, disability, and difference
5. The importance of having genetically related children
6. The kind of future people desire or fear

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A small minority of participants made strong statements that, once conception has taken place, the embryo has the full value of a human life; therefore, destruction of preimplantation embryos is equivalent to killing a baby, and the use of PGD is immoral. These participants were almost exclusively self-identified Evangelical, Catholic, or Mainline Protestant Christians.

[W]hat I would call [PGD] is selective abortion because I believe that life begins at conception, which is when the sperm and the egg unite. So, whether it is eight to 10 cells, or a fully developed baby, I think what you have done is scientifically produce 20 ... bab[ies] ... Based on the fact that I think it's a baby at conception, then what is happening is abortion, and I disagree with abortion because I think it is taking a life. (*Participant from Evangelical women's group, Colorado*)

For participants who felt that the destruction of embryos and fetuses is morally equivalent, PGD was sometimes considered to be more ethically problematic than prenatal diagnosis and abortion.

I think the difference is that when you're testing the embryo at 4 months, you've only created one potential life there. When you do it in the dish, five, six, seven, eight? Those are all potential children. So to me, that's the difference. You have now created more that are going to be destroyed. (*Woman from mixed sex/race group, Massachusetts*)

A very small minority of participants thought that taking a chance, conceiving naturally, and aborting an affected fetus would be a better alternative to PGD because of the expense, physical risk, and low pregnancy rates associated with IVF and PGD. Their reasons for suggesting this option were complex, but, for them, risking an affected pregnancy and having an abortion was a reasonable choice.

So it's just making me think now maybe they're better off trying [natural conception] again, and having the amnio[centesis], and then having to make that decision again, whether you can carry forth with it. As opposed to spending all of this money, all of this emotional everything. Well, of course it's emotional either way, but the chances of having a healthy baby in the end are actually better if they do it on their own. (*Participant from Jewish women's group, Massachusetts*)

In the scenarios, participants were asked to consider what they thought about an imaginary situation in which a scientist could genetically modify an embryo. For some, assuming it was safe, the modification of a single embryo to avoid disease was preferable to creating and then selecting from multiple embryos with PGD because it might avoid the intentional destruction of embryos. Similarly, many participants favored sperm sorting over PGD to avoid X-linked genetic disease because no embryos would be created or destroyed in the process.

Nature of the Disease or Characteristic Being Avoided or Sought

The perceived severity of the genetic disease or condition was a key factor in determining the appropriateness of using RGTs. Most participants agreed that avoiding life-threatening illnesses with an early onset (Tay-Sachs disease, cystic fibrosis, thalassemia, sickle cell anemia) was an appropriate use of RGTs. Support declined for the use of RGTs to avoid the birth of children with diseases or conditions (such as colon cancer) that were less severe, non-life threatening, or that would not show symptoms until adulthood.

It gets into a very gray area when you're saying "Now we're going to have a child who is going to be sick from day 1, and it's going to be sick for its whole life" versus "Now we're going to have a child that's going to be healthy for 40 years, and maybe by then we're going to have a cure for cancer." (*Woman from mixed sex/race group, Massachusetts*)

Participants were asked to assume that alterations in the genes might someday be identified that contribute to the development of conditions and traits like obesity, depression, and intelligence. They were then asked to discuss whether they would support the use of RGTs for these purposes. There was less support for the use of RGTs to avoid diseases and conditions such as obesity or depression, which participants thought could be prevented or treated through medications or behavioral modifications. There was little support for selection of traits like intelligence.

However, participants in several groups acknowledged that what is inappropriate or "trivial" is not black and white. The discussions about the use of RGTs to avoid obesity, for example, usually began with one participant calling it "vain" while others felt it was a legitimate health concern, leading the group members to realize that both points of view were defensible. Similarly, participants would use terms such as "quality of life," "life-threatening," and "severe" only to discover that they each defined these terms differently.

Some participants within every focus group argued that the desire to have children with specific traits (such as blonde hair) is morally wrong. They argued that these frivolous uses of RGTs are rooted in human vices like "vanity," "selfishness," and "underhandedness." Using RGTs is perceived by many to be the most effective means to avoid genetic disease, but participants were still concerned that development of the technology for one purpose will inevitably lead to use and abuse for other purposes. Ultimately, though, participants were sensitive to the fact that an individual's perceptions about the severity of suffering or potential impact on quality of life caused by a disease or condition is extremely personal.

Technological Control over "Natural" Reproduction

Beliefs about how much technological control people ought to exercise over the reproductive process were also diverse. At one end of the spectrum were people who believed that

technological intervention in reproduction, especially when it involves the manipulation of embryos, is unnatural or playing God. At the other end were people who believed there is a moral obligation to improve the human condition through all forms of technological progress. Participants who thought that technological intervention in reproduction was problematic gave both religious and secular rationales.

I don't think that you can just discard an embryo that has been fertilized, or change that in any way because I just don't believe that that is the way God intended it to be ... I think that's an ethical thing, and I think that's God choice and not mine, or the doctor's or anybody else's. (*Participant from Catholic Caucasian women's group, Michigan*)

The themes that using RGTs is playing God and that manipulation of embryos outside the womb is unnatural were common in many of the focus groups, not just those with religiously oriented participants.

An additional objection to RGTs was that people do not have the right to decide who gets to be born based on an assessment of potential quality of life. This view was expressed predominantly by Evangelicals and Catholics. Similarly, some Evangelicals and Mainline Protestants argued that everything in life happens for a reason as a part of God's divine plan and that using RGTs reflects a lack of faith in God's plan for one's life.

I believe that everyone is created differently, and there is a reason that people are born with whatever. Even if it is cystic fibrosis, there is a reason that God has intended that person to have that, whether it be a testimonial kind of a thing, or maybe it would make the quality of life better, knowing that you could die within like 10 years, because I think a lot of people just live like they can live forever ... So I think everything has a purpose. (*Participant from Evangelical women's group, Colorado*)

Participants' opinions about RGTs reflected their views about what they believe it would be like to raise a child with a genetic disease. For many Evangelical and Mainline Protestant participants, having an affected child is a test of faith for the parents or a testimony of faith to others.

[D]o you trust God to have the best will, that what he has given you is the best thing that you can have, and to do the best you can with it, or do you want to keep intervening in situations, and change things, and not knowing whether you have the best wisdom or not? (*Participant from Evangelical women's group, Colorado*)

When challenged by other participants, some of those who thought that RGTs are unnatural or playing God were persuaded that using RGTs to avoid disease is not all that different from other medical interventions.

[I]t sounds morally wrong, but I can't really distinguish why it would be any different ... as opposed to just give [a person] a pill or make a vaccine or something, and it would have the same exact effect by curing the disease. (*Participant from young men's group, Tennessee*)

A few participants maintained, and many others were receptive to the idea that God has given us these technological tools and leaves it up to people to use them wisely.

[I]f we're going to leave it to God, God's putting this knowledge in our path ... God's giving us the knowledge to figure it out. (*Participant from Mainline Protestant women's group, Massachusetts*)

Some participants believed that an ability to select embryos based on certain characteristics or to modify humans will not have a net positive effect on the world because humans cannot be trusted to make wise choices about appropriate uses. These participants were concerned that greed, vanity, and prejudice would drive both individual and policy choices. Children might be selected for or designed based on superficial or even potentially harmful traits rather than traits that might be truly beneficial to these children or the community. Next, participants thought that we do not have an adequate understanding of potential negative consequences of altering human DNA. Finally, because many traits result from a combination of genes and environment, focus on a single genetic contribution would set up unrealistic expectations. For instance, the idea that increased intelligence does not make a better person unless it is paired with motivation and compassion was a common theme.

[Y]ou may give me a Rhodes Scholar, but he still may be Ted Bundy. (*Participant from African American men's group, Tennessee*)

A very different perspective was expressed by a small number of men in a few of the focus groups. They argued that technological intervention in reproduction can lead to efficient and vast improvements in human capabilities in any number of dimensions, and we have an obligation to pursue technological progress.

It's kind of funny that I guess humans will do this to animals to make more productive cows, more productive chickens that have bigger breasts for meat and stuff like that, and we can look at that as an improvement of the animal for a variety of purposes, but we kind of refuse to put ourselves in that animal category, and we refuse to say "Why don't we make a smarter kid?" As a teacher, I would love to have a room full of smart kids. I have plenty on the other side, you know? (*Participant from Caucasian men's group, Colorado*)

Value of Suffering, Disability, and Difference

Many participants discussed use of RGTs in terms of the role and value of suffering in people's lives. Although most viewed suffering in uniformly negative terms and as something that ought to be avoided, a minority of participants argued that affliction is a valuable part of life and contributes important opportunities for growth to individuals, families, and collectively, to society.

I have clinical depression and society anxiety. Although some [diseases] do cause a lot more problems than others,

everyone has got obstacles in life to get through, and if you terminate all of [these people] from the very beginning to where people have an almost perfect existence, that eliminates a little challenge from life. And having things like this to get through, no matter how extreme they are, or how some of them might pale in comparison to other ones, they still, sometimes they can give people a reason to try harder, or a reason to build themselves up to be better than they are. (Participant from young men's group, Tennessee)

Among those who thought that affliction is a valuable part of life were those who believed that disability and personal challenges contribute to a more diverse and humane world. They thought that widespread use of RGTs would reduce the number of people with disabilities or genetic disorders, ultimately resulting in a reduction of our understanding and acceptance of those who are different. This loss of compassion could ultimately lead to a loss of "what makes us human."

I'm saying the more and more that these technologies become available to humans in general, the more and more this will just be another means that we'll use to be less than what we should be. (Participant from African American men's group, Massachusetts)

Selection against what we consider to be physical "flaws" that cause suffering or create challenges could deprive the world of the contributions made by these people, particularly when the "flaws" are a part of what make them special. Participants mentioned the contributions of artists like Van Gogh, who suffered from mental illness, and Helen Keller.

I think that creative genius probably is a genetic flaw. I think the people who are creative geniuses have plenty of traits, which really are not easy to deal with. And it seems like a lot of what we're talking about is "let me get rid of things that are hard to deal with," like obesity or having a learning disability. (Participant from young men's group, Tennessee)

On the other hand, many participants expressed the view that the alleviation or prevention of suffering, particularly in children, is desirable; in fact, some thought parents have an obligation not to bring an affected child into the world.

[A couple who already have a child with a genetic disease] have all kinds of options. I just think it would be selfish if they decided to [reproduce] together. (Participant from Chinese women's group, California)

You have a responsibility to bring a child into the world with a certain quality of life. (Woman from mixed sex/race group, Massachusetts)

A number of participants mentioned that the burden on a family of having an affected child was relevant to the decision-making process. Participants said that the emotional and financial burden of raising a disabled or sick child, the burden on siblings, the effect on the stability of the parents' marriage, potential parental guilt at having given a child a genetic disease, and concerns about loss of family health

insurance might factor into a decision about whether using an RGT was or was not appropriate. Many participants thought that the potential ability to wipe out a genetic disease from a family was a very compelling benefit of some RGTs.

If [genetic modification] worked, it would stop [the gene mutation] from going on to the next generation ... You can have kids, and kids, and kids, and it will just go away. (Participant from African American women's group, Michigan)

Importance of Having Genetically Related Children

When participants considered the appropriateness of using certain RGTs given a risk of having a child with a life-threatening disease, they usually factored in the importance or lack of importance of having genetically related children. Many participants stated or implied that having genetically related children is a legitimate desire, and that adoption, gamete donation, or not having children were not acceptable alternatives for everyone.

[I]t seems to me that one wants to continue oneself [through reproduction]. I don't call it ego, so much, I call it ... a natural desire. (Man from older mixed sex/race group, California)

I think ... having a child is very personal and intimate with your spouse, but having a child that's half yours ... one of you is missing something. (Woman from mixed sex/race group, Massachusetts)

For others, the low success rate of IVF; existing children in need of adoptive homes; and the risks, costs, and burdens of using RGTs to have biologically related children made RGTs less attractive than the alternatives.

I would save the hassle and all and just adopt because there are plenty of kids that need to be adopted [rather] than going through all of these procedures and not knowing exactly physically what might happen. (Participant from young men's group, Tennessee)

Kind of Future People Desire or Fear

Focus group participants' perceptions about the social consequences of widespread use of RGTs were important in their evaluation of the use of RGTs. Although most participants were enthusiastic about the potential to avoid suffering caused by genetic disease, the four most frequently mentioned negative social implications were: disparities in access to technology creating greater economic, racial, and health disparities; discrimination against and stigmatization of people with disabilities; commodification of children; and adverse population outcomes.

Participants voiced concern that RGTs would not be available to everyone because of disparities in insurance coverage and ability to pay, and because providers might not offer it equally to all. This inequity in access could lead to greater economic and health disparities because those who have the

least resources would be responsible for raising children affected by genetic disease or children who do not enjoy the benefits of genetic modification.

[W]e are going to see communities who are cancer free, and we are going to see other communities who can't seem to live past 30. So it's going to just totally reshape society. *(Participant from African American men's group, Tennessee)*

I see a world where only poor people have diseases. *(Participant from group of women with no children, California)*

The notion that this technology will not be available to some, or might even be used to harm groups was especially prominent among the African American and Latino groups.

What if they all of a sudden say, "Hey, let's just eliminate all Mexicans?" [We're] gone. *(Participant from Mexican American women's group, California)*

[V]ery rarely has the majority instituted anything into our community that created a positive effect. This is dangerous. *(Participant from African American men's group, Tennessee)*

Second, there was concern that the ability to avoid the birth of affected individuals might result in increased discrimination and stigmatization of those already living with genetic disorders and lead to social neglect of this population.

There [would be] fewer people who are sick, but there's less attention given to the sick people. Like there's less ... priority given to those diseases. I would want to make sure that, even though they're a minority, that they're still being taken care of somehow. *(Woman from mixed sex/race group, Massachusetts)*

Numerous participants stated that RGTs should not be perceived to be a substitute for continued research into cures for genetic disease.

Third, participants were concerned that the ability to use the technology to design a child—"picking and choosing" traits the way you would "customize a car"—fuels negative human tendencies like selfishness and vanity. There was concern that increased use of RGTs could change the way we think of children and increase the chances that we view them as commodities. Some participants were concerned that the technology will create unrealistic expectations that it is possible to create perfect children. Others worried that competition might develop between people in the pursuit of having better children.

To me, if I have a kid, they can read, sing, dance, smile, I'm happy. But some people, they push their kid, you know, they want them to be the best. So what? IQ what, 100, 200, 300? What's the level? And if everyone in here, we all say, okay, we want our kid more intelligent. So your kid is 150 [IQ]. I find out, I want mine 180. Oh my God, that would be a world war around the medical thing. Ech, no, don't go

there. That's too far. *(Participant from Chinese American women's group, California)*

The fourth concern was that the use of these technologies might have widespread species or population effects. Concerns included overpopulation, sex-ratio imbalances, loss of genetic diversity that could lead to greater susceptibility to infectious disease, and other unknown detrimental effects.

But we all know for a fact that humanity is strong because of diversity. Now it may not be as clean. Yes, we have kids with cystic fibrosis. We have kids with Down syndrome, but diversity is what makes us strong ... we don't know what the future implications of our eliminations are. *(Participant from Caucasian Protestant women's group, Massachusetts)*

Although the potential for sex-ratio imbalances worldwide was a concern, focus group participants were less concerned that this would become a significant problem in the United States where children of both sexes are valued and desired.

DISCUSSION

Participants in this research had robust discussions and appeared to be very interested in the topic. We attribute this in part to the presentation of scenarios in which participants were able to perceive the issues that uses of these technologies present, confront them directly, and yet depersonalize them because questions addressed how participants would counsel a friend or family member. These discussions resulted in a detailed, textured picture of participants' beliefs and values that shaped their overall opinions about the use of these technologies.

Focus group transcripts revealed six key factors used by participants in determining the appropriateness of using a given RGT. Participants considered their beliefs about: [1] the possible destruction of embryos; [2] the nature of the disease or trait being avoided or sought; [3] technological control over "natural" reproduction; [4] the value of suffering, disability, and difference; [5] the importance of having genetically related children; and [6] the kind of future they desire or fear.

Individuals weighed the six factors differently. Some participants felt very strongly about a specific factor while others were ambivalent. For instance, for those who believed that adoption was a better alternative than using RGTs to create a family, the other issues were less salient and, in some cases, were simply dismissed. In many cases, participants struggled as they weighed perceived benefits and risks. For instance, avoiding the profound suffering of a child often outweighed peoples' concerns about the intentional destruction of preimplantation embryos or the belief that the outcome is "God's will." Another poignant example of this tension between values was evidenced by participants' desire to embrace diversity and accept those with disabilities while at the same time holding parents accountable for the suffering caused by genetic disease when they knowingly take the risk of having an affected child. Although there was

never perfect agreement, a majority thought that it was appropriate to use these technologies to avoid life-threatening disease, and a majority thought that use for trait selection was inappropriate.

The most novel finding from this study was the link between participants' beliefs about the nature and purpose of suffering, disability, and difference and their beliefs about the appropriateness of using RGTs. This is an important finding because frequently presentations of the divisiveness in views about the moral appropriateness of these technologies are attributed solely to differences in views on the moral worth of embryos. Our results suggest that while important, this is not the only concern.

Even though many participants had strong views about whether the use of RGTs was or was not appropriate, most, despite their own strong point of view or preference, stressed the importance of individual decision making. Because the choices we presented, and the consequences of those choices, were so profound—as many reproductive choices are—most participants ultimately felt that only the couple themselves could or should make the decision to use RGTs. In contrast, a minority of participants believed that the potential negative social consequences of widespread use of RGT are so significant that individual freedoms may have to be limited. Participants were universally opposed to people being coerced or pressured to use RGTs by government, health care providers, or health-insurance coverage policies.

This study provides new insights into some Americans' beliefs and values about the use of new RGTs. These themes can now be tested in a representative sample to determine whether and how Americans' opinions differ by sociodemographic characteristics or other factors. Because new RGTs are being developed and introduced into clinical practice in a social and political environment where tensions around reproductive issues are high, it is important for health care professionals, professional societies, and policy-makers to have a comprehensive understanding of the public's beliefs and values. Our research demonstrates that public opinion, specifically around the use of new RGTs, does not fall neatly into classic pro-life or pro-choice arguments. With the issues of concern to Americans now identified, health care providers have the chance to consider these beliefs and concerns when they communicate the benefits and risks of these technologies to the American people, when they convey the intended goals of research and development of new RGTs, and when they craft practice and ethics standards for appropriate use of these technologies. Decision makers in both the public and private sectors have the opportunity to develop policy that genuinely respects and reflects American values.

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