

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

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