

Religious Guidance and Care Regarding Genomic Testing

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Introduction

Genetic testing in the U.S. is rapidly expanding as a result of the Human Genome Project and advances in technology. At the same time there has been an increase in (1) older women desiring pregnancy with the associated infertility, increased risk for birth defects, and use of IVF; (2) expansion of prenatal testing to younger women; (3) expanded state mandated newborn screening; and (4) the availability of genome-wide scans with full human gene sequencing on the horizon. While genetic counseling is provided in many of these situations, the decision to test and reactions to test results may raise ethical and religious issues that genetic counselors may not be fully prepared to address. Decisions require extended support and counsel not usually available in a genetic counseling session. Clergy and leaders of religious communities may be increasingly called on to provide support and counsel to members of their communities facing difficult issues related to genomic testing. Are they adequately prepared to respond?

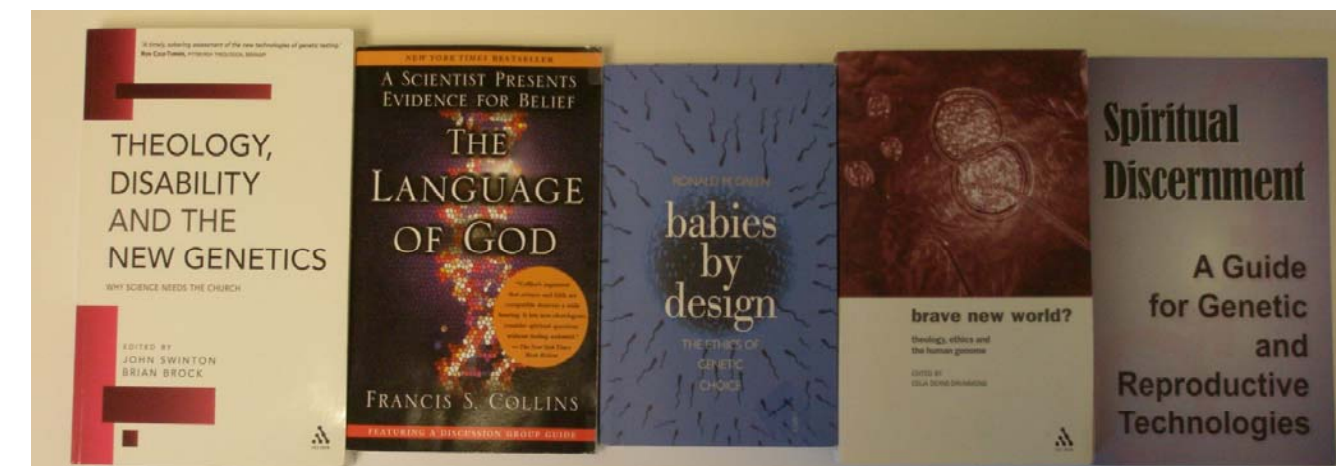
Background

"Many of you know that we were going to the doctor today to find out the gender of our baby...Unfortunately, during our ultrasound, we received some very sad news...the diagnosis is Trisomy 18. [We] had a very discouraging visit to the fetal specialist yesterday...we are overwhelmed with all the information. We continue to seek God's wisdom and healing for Rachel, even though it's often through tears."
Personal reflection, Bob and Mia Xia Hoffman

New Era, New Worry: New tests for Down syndrome could lead to more abortions and less support for families.
Article in Newsweek magazine, December 6 2008

Response: Dr. Scheib and Professor Faucett co-taught the course **"Pastoral Dimensions of Bioethical Decisions"** in **January 2009**. The course was designed to prepare religious and pastoral leaders to provide informed and compassionate care to members of faith communities faced with making difficult decisions about the uses of biomedical technologies.

Course Materials



Books exploring the intersection between genetics and religion.

"This course talked about issues that are new in science but raise significant theological debate."
Class participant

"Both Professors worked well together. Having the counseling perspective from both provided insight about how to talk about these issues."
Class participant

"The course made me profoundly aware of genetic and theological issues. I believe all seminarians should take this course."
Class participant

"The interplay between the two professors from the perspectives of theology and medicine enhanced the course."
Class participant

Aims

The goals of this project are:

- 1) to measure clergy's current knowledge regarding genetic and reproductive technologies;
- 2) to explore clergy reports about the frequency of requests for support from members of their religious communities and how often clergy are comfortable providing counsel and guidance regarding these issues
- 3) to explore the experiences of members of religious communities in terms of how they dealing with issues regarding testing based on self reports and published data

Methods – Phase I

Survey of Religious Community Professionals

During the first phase of this project, alumni from the Candler School of Theology and Atlanta- area rabbis will be asked to participate in an on-line survey. Participants will be recruited with the assistance of the Candler School of Theology Development Office, and through contacts with the Emory Center for Ethics. The survey will consist of questions about the participant's background knowledge in genetics, demographic information, professional duties, and involvement in pastoral counseling about genetics issues. The survey should take approximately 15-20 minutes to complete, and we hope to recruit 1000 participants.

Survey

Survey: Religious Guidance and Care Regarding Genomic Testing

Practices and Policies:

1. I have or am currently providing counseling to persons about the following:
 - Prenatal genetic testing _____
 - Pre-implantation genetic testing _____
 - State mandated newborn screening _____
 - Genetic testing of children _____
 - Adult genetic testing for diagnostic purposes _____
 - Genetic testing ordered directly from a company without the guidance or input of a medical professional _____
 - None of the above _____

2. Do you know whether your religious community has established positions on issues of genetic testing? (Yes/No)

3. I have deeply held religious convictions about the following values that influence my counseling on the above topics (check all that apply):
 - Sanctity of Life _____
 - Reproductive choice _____
 - When life begins _____
 - Quality of life _____
 - Other _____

Genetic Knowledge:

4. Women are more likely to inherit an increased risk for breast cancer from their mother than from their father.
(True/ False)
5. Most birth defects are due to maternal exposure to drugs or alcohol.
(True/False)
6. The risk for a chromosome abnormality increases with maternal age, and as a result most children with Down syndrome are born to women over age 35.
(True/False)

Select Questions from Survey of Religious Community Professionals

Methods - Phase II

Congregant Focus Groups

In Phase Two of the project, focus groups of 5-10 persons will be held in Atlanta-area congregations to discern how often members report seeking guidance from their religious leaders regarding genetic testing, genetic illness, and reproductive technologies. Information learned during the first phase of the project will inform the development of the questions to be used in guiding the focus group discussions. We will compare the religious leaders' self reports about providing counseling for genetic issues with the congregant self-reports about requesting counseling.

Progress

- Completed
- Survey Questions
 - Agreement to survey Candler alumni
 - IRB Submission
- In Progress
- IRB Revisions
 - "Survey Monkey Tool"
 - Selection of Congregations for Focus Groups

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Acknowledgements

This project could not be completed without the financial support of the Emory Religion and Public Health Collaborative, as well as the cooperation of the Candler School of Theology Development Office, Candler Alumni, and Atlanta-area rabbis.