Virtual Mentor. May 2003, Volume 5, Number 5.
doi: 10.1001/virtualmentor.2003.5.5.pfor1-0305

Policy Forum

The Virtue of Drawing Lines in Genetic Testing

While there are benefits to genetic screening during pregnancy, parents must not let their desire for a genetically perfect child allow them to terminate a pregnancy because of non-medical factors.

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At present it is possible to test for a wide variety of genetic diseases (both single gene disorders and chromosomal abnormalities) at the preimplantation state (through pre-embryo biopsy) or sometimes during the course of gestation (through maternal serum screening, ultrasound, chorionic villus sampling, and amniocentesis). Such tests are usually offered only for serious genetic diseases such as cystic fibrosis, Duchenne muscular dystrophy, Tay-Sachs disease, hemophilia A and B, Betathalessemia, sickle-cell disease, a -1-antitrypsin deficiency, fragile X syndrome, Lesch-Nyhan syndrome, Down syndrome, and neural tube defects. Moreover, they are usually offered to prospective parents only for established medical reasons. For example, preimplantation genetic diagnosis (PGD), is indicated when a couple has been "psychologically traumatized by repeated pregnancy loss due to genetic disorders" [1] or has had a child with a serious genetic disease previously and is at high risk for having another. Similarly, prenatal genetic testing is indicated when 1 or more of the following conditions is met: (1) advanced maternal age (age 35 and upwards), (2) a family history of genetic abnormalities, (3) membership in an ethnic group that is at risk for a specific condition (eg, Tay Sachs in Ashkenazi Jews, sickle-cell anemia in African-Americans, and cystic fibrosis in Caucasians), (4) a family history of infants with birth defects, and (5) multiple miscarriages.

The present state of affairs is unlikely to remain the same for much longer, however. As genetic tests become available for mild genetic diseases and susceptibilities to genetic disease as well as for a greater number of serious genetic diseases, and as the public becomes increasingly aware of the existence and availability of such tests, prospective parents may demand as much in the way of tests for their future children as their wallets can afford. Some of these prospective parents will want the information to prepare for life with a child that may be born with significant physical and mental disabilities. But others will want the information for the purposes of discarding their pre-embryos or aborting their embryos. Indeed, there is considerable evidence that a high percentage of prospective parents already choose to eliminate embryos with Down syndrome, for example [2]. There is also increasing evidence that a significant percentage of prospective parents would consider aborting their embryos if they had only a slight genetic disease, a susceptibility to genetic disease, or a characteristic that did not mesh with one of their preferences (for example, a preference for a boy as opposed to a girl). In one study, researchers surveyed a sample of prospective parents about what type of genetic risks would lead them to terminate a pregnancy. They discovered that 1 percent of the surveyed couples would terminate a pregnancy if the fetus was not the sex they wanted; 6 percent would abort a fetus susceptible to Alzheimer's disease; and 11 percent would abort a fetus susceptible to obesity [3].

Studies such as the one above have triggered heated debates about procreating "less-than-normal" children. Advocates of procreating only "normal" children claim that it is emotionally and economically draining to bring children with disabilities into the world, especially if they have serious genetic diseases or disorders. Furthermore, they argue that it is not in the best interests of such children themselves to be forced to live difficult lives that could have been avoided if only their parents had acted responsibly.

Critics of the "normal" children only argument claim that it reinforces the view of those who long for a society in which only perfect or nearly perfect people are tolerated. They point out, as does lawyer Lori B. Andrews, that the

concept of "normality" is a moving target. She claims that as genetic testing becomes available for a greater number of genetic characteristics (most of them non-medical), our understanding of what is normal and what counts as a life worth living will be continually "upgraded" [4]. She cites approvingly the views of Michael S. Lagan, a vice president of the National Organization for Rare Disorders, who has commented that "Eventually there will be discrimination against those who look 'different' because their genes were not altered. The absence of ethical restraints means crooked noses and teeth, acne or baldness, will become the mark of Cain a century from now" [5]. Like others who wish to slow the march towards genetic perfectionism, Andrews and Lagan are particularly concerned that prospective parents will increasingly feel they have not simply a *right* to test their embryos for genetic disorders and diseases, mild as well as serious, but a *duty* to do so with a view towards aborting embryos that prove to be less than completely "normal."

The current consensus of clinicians is that it is wrong to pressure women to abort "less than normal" embryos. As they see it, couples in general and women in particular must decide whether, in each particular case, they should or should not bring into the world a child with a *serious* genetic condition. However, clinicians are not presently of one mind with respect to advising prospective parents who wish to abort embryos affected by a *slight* genetic disease (eg, myopia), a *susceptibility* to a genetic disease (eg, cancer), or a *non-disease*-related genetic characteristic (eg, sex). Some clinicians believe that it is up to prospective parents to decide what they consider a "normal" child; but others insist that judgments about "normalcy" belong to the public as a whole.

One way to prevent prospective parents from terminating pregnancies of embryos not affected by serious genetic diseases and defects would be to withhold from prospective parents information about their fetuses' slight genetic diseases, genetic susceptibilities, and generally non-health related characteristics (eg, sex) [6]. But the *medical* justification for this policy is not altogether clear, unless test results for such genetic characteristics are highly inaccurate, difficult to interpret because of the way in which environmental factors influence one's genetic health, or very costly. Thus, an increasing number of clinicians who value autonomy over paternalism believe that absent such considerations, they have neither a right nor a duty to withhold from prospective parents any of the information they discover about the embryo's genetic condition. Not only do they reason, as mentioned above, that it is up to prospective parents to decide what kind of child they are ready, willing, and able to raise, they also reason that if a woman decides to exercise her right to have an abortion, it does not matter to the law whether she does so because her healthy fetus is male rather than female, because she and her husband do not have the means to rear a child, or because her fetus has tested positive for Tay-Sachs disease. Finally, some clinicians stress that if clinicians prevent prospective parents from learning everything there is to know about the genetic status of their child, prospective parents will simply turn to technicians outside of the health care realm for this information. Better, they say, for prospective parents to be properly counseled and advised by trained clinicians who can guide them to wise reproductive decisions than to leave them to the vagaries of self-administered, in-the-privacy-of-your-own-home genetic tests, the results of which are sent to a distant lab which, in turn, sends prospective parents a print-out of their fetus's complete genetic status.

Although I agree that if clinicians draw lines about the kinds of genetic tests they offer, some unscrupulous technicians may arise to take advantage of prospective parents, I still think that clinicians should continue to valiantly steer between the Scylla of patient autonomy run wild and the Charbydis of clinical paternalism grown arrogant. Medicine is not simply a set of techniques and tools that may be used, willy-nilly, to attain whatever ends people have, and clinicians are far more than mere technicians who simply have a bag of skills to sell to the highest bidder. It would be a colossal shame if, in the name of preventing prospective parents from turning to an irresponsible and amoral technician-entrepreneur class that may or may not arise, clinicians find themselves no better than their rivals. Better to continue the hard work of line drawing, and all the human disagreement and tension that entails, than to destroy the hard-won and long-sustained internal morality of medicine and with it one's own ideals.

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4. Andrews LB. *The Clone Age: Adventures in the New World of Reproductive Technology*. New York: Henry Holt and Co; 1999:162.
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5. Andrews, 147.
6. Sex is a medical criterion when an X-linked recessive condition such as hemophilia is present.

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