Introduction

This chapter discusses whether pregnant women ought to obtain reproductive genetic testing. This topic, and the particular way of framing the issues it represents, is, however, by no means the only or even the most important ethical consideration raised by reproductive genetic testing. Larger questions about the implications of advances in that area for the meaning of moral community are at least partially pushed to the background when the moral issues are particularized to the individual mother and child. Indeed, it could be argued that, from the standpoint of women, as well as that of persons with disabilities, it is on this wider social plane that the moral stakes are the highest.

Having said that, it is clear that reproductive genetic testing confronts each of us as individuals, as pregnant woman or other, with important ethical questions. From the perspective of the morality of personal action, at least four kinds of questions need addressing:

1. Should pregnant women seek reproductive genetic testing?
2. Should pregnant women accept offers of reproductive genetic testing?
3. Should pregnant women seek or accept therapeutic interventions suggested by genetic testing?

4. What, in the absence of therapy, should pregnant women do when a fetus is identified as having a "problem"?

Two Approaches

Consider the following proposition. Pregnant women ought to take reasonable steps to use genetic technology to prevent or reduce illness or disability in their prospective children (fetuses that pregnant women are carrying to term). A defense of this proposition can be constructed in numerous ways, including both a traditional analysis from principle and an analysis from an ethic of care (an ethic of care being one of several contemporary challenges to traditional moral theory with ties to feminism and feminist moral psychology [Blustein, 1991; Carse, 1991; Sherwin, 1992]).

In an analysis from principle, the central task is determining whether there exists a maternal duty to employ genetic interventions, where duty is understood as a fixed obligation grounded in either a single moral principle or some combination of moral principles. The most promising candidates for grounding a maternal duty to employ genetic interventions are the principles of nonmaleficence and beneficence.

The principle of nonmaleficence holds that one ought not inflict harm or evil upon others. The implications of this powerful but general moral injunction for parental duties toward genetic testing are not, however, straightforward. Jeffrey Kahn has undertaken the most exhaustive analysis of this topic to date. As Kahn points out, it is by no means clear whether the passing on of a "bad gene" constitutes the inflicting of a harm, nor is it clear in what sense persons can be harmed by their genes, or what act (such as conception, failing to terminate the pregnancy, or failing to interfere with the pregnancy) is the particular act that harms.

By contrast to the complexities of relating maternal duties to nonmaleficence, an analysis from the principle of beneficence
has considerable intuitive appeal. Although the principle of beneficence is also concerned about harm—its removal or prevention—the principle primarily considers duties in terms of conferring benefits or seeking the best interests of others. Thus, for genetic testing to fall under the scope of the beneficence principle, thorny conceptual problems about the nature of harm and harming need not be resolved. All that is required is an assumption that the interests of offspring would best be served, that offspring would be better off, if their mothers were to employ (at least some) genetic interventions.

The problem with applying the principle of beneficence is the principle's indeterminacy, its disputed moral standing with respect to the imposition of strict moral duties. There is virtually no dispute that individuals have strong (negative) obligations to refrain from harming others. By contrast, there is considerable disagreement about whether, under what conditions, and to what extent individuals have positive obligations to benefit others. The central problem is how to fix such duties of beneficence. A typical maneuver is to move from an analysis of general duties of beneficence to an analysis of duties specific to particular roles. That is, even if we cannot agree about the existence of general moral obligations to benefit others, surely certain roles carry with them very fixed and specific duties to benefit others. A paradigmatic such role is that of mother. Assuming we can accept that mothers have strict duties of beneficence toward their children, an application to the context of reproductive genetic testing requires evidence that the use of at least some such testing falls within those duties. For this claim to be sustained, it is necessary to establish that maternal duties of beneficence apply to prospective children as well as children already born, and that the use of (at least some) genetic interventions are in the best interests of those prospective children.

The question of whether pregnant women ought to take reasonable steps to use genetic technology to prevent or reduce illness or disability in their prospective children can also be approached from the perspective of an ethic of care. Rather than working from a structure of moral principles, the focus of a care-based ethic is on the moral nature of relationships and on a way of thinking about the moral life that has as its foundational
moral categories not rights and duties, but commitment, empathy, compassion, caring, and love. Here again, the paradigmatic context is the family and, especially, the parent-child relationship. It has been argued, I think correctly, that the parent-child relationship is better analyzed in terms of moral categories like caring, compassion, and love than by a language of impersonal, objective rights and duties (Blustein, 1989). Indeed, it seems incontrovertible that caring and love rest in the essence of parenting, that what it means to be a parent, above else, is to care for and seek the welfare of one's child. Ensuring or enhancing the health and functioning of one's child is surely part of what it means to care for one's child. Thus, insofar as reproductive genetic testing and related interventions can contribute to the (prospective) child's welfare, seeking such interventions would fall within the moral territory of parenting.

There are many ambiguities, many unanalyzed nuances in this sketchy presentation, both with respect to an analysis from principle or from an ethic of care. One common point worthy of emphasis, however, is that neither approach relies on any argument that is unique to genetics or to reproduction. In both cases, the appeal is grounded in a general understanding that mothers are supposed to seek and protect the health of their children—including taking reasonable steps to prevent illness or disability—and that, at least in theory, genetic testing can contribute to that end. What is left open in this sketchy treatment is the specific meaning of such critical terms as prevention and "reasonable steps." Although a careful analysis of these complex concepts is beyond the scope of this chapter, a few comments are in order.

Prevention

Despite prevention's venerable history in medicine, and especially in public health where the term has been parsed in numerous ways, no rigorous analysis exists of what it means to prevent illness or disability (as opposed, for example, to treatment or rehabilitation). Particularly with respect to genetics, the boundaries of the concept of prevention remain largely uncharted. Perhaps the most troubling question is whether or in
what sense the term prevention can be applied to eugenic policies and practices. For example, when a program of maternal serum alpha-fetoprotein screening results in the abortion of ten fetuses identified as having neural tube defects, is this conceptually or morally analogous to a hypertension screening program’s resulting in the averting of ten cases of untreated malignant hypertension?

From a moral perspective, the answer to this question is an emphatic No. Eliminating an incident of disease or disability by “preventing” the person who would have that disease or disability from being born is not an instance of prevention—not in the sense in which it is ordinarily meant and not as the term ought to be used. As has been argued elsewhere, treating the prevention of the birth of children who would have an illness or disability as morally equivalent to preventing illness or disability in persons already living involves a morally unacceptable view of the worth of such persons (Asch, 1989; Faden, Geller, & Powers, 1991). It suggests that the lives of some persons with a disability or illness are not worth living, that such persons are to be understood only as social or economic drains and never as sources of either independent value or enrichment for the lives of others.

From the perspective of the morality of mothering, it similarly can be argued that preventing illness or disability in children already living is morally different from preventing the birth of a child who would have an illness or disability. Maternal commitments to care for one’s children, to seek their interests, and to spare them disease and disability thus do not extend to or encompass preventing the birth of such children (whether by selective abortion, selective conception, or remaining childless). To hold otherwise, one must be able to argue that it is in the child’s interests not to be born, that life with the disease or disability is so poor and aversive that it is a life not worth living or a life worse than no life at all.²

Can this condition ever be satisfied? According to some commentators the answer to this question is no, if only because the comparing of any state of existence with nonexistence is metaphysically or logically impossible (Tedeschi, 1966). Still others have argued that such a comparison is possible and that non-
existence may indeed be preferable when, for example, it would be rational to prefer death to existence or when all and every interest in life is doomed from the outset (Feinberg, 1986; Parfit, 1986).

It is arguably the case that very few genetic disorders meet such criteria. (Lesch-Nyhan syndrome, a devastating genetic disease that results in mental retardation, self-mutilation, and renal failure, may be one such instance.) It follows that, allowing for the rare exception, there is no requirement in mothering to seek or accept reproductive genetic testing if the only actions facilitated by such testing are abortion, selective conception, or remaining childless. Implicit in this position is a rejection of abortion as, in any sense, a therapy for the fetus. Moreover, as a pragmatic matter, this means that today, given the paucity of effective, available therapies, women striving to be good mothers should not feel under any obligation to accept reproductive genetic testing out of a sense of commitment to or compassion for their prospective children.

It does not follow from this position, however, that seeking reproductive genetic testing for purposes of selective abortion is necessarily morally wrong. The claim is only that, from the perspective of the moral context of mothering a prospective child, no moral requirement to have reproductive genetic testing exists in the absence of effective therapy for that child. This said, it must be recognized that commitments to other family members or to oneself can provide reasons to elect genetic testing and selective abortion and that those reasons may be morally or prudentially compelling.

Reasonable Steps

Assuming an effective therapy for the prospective child is available, what can pregnant women reasonably be expected to endure in the way of personal hardship, loss of liberty, or risk of harm in order to secure that therapy? The answer to this question is in many respects more difficult than are those to questions about prevention and genetic intervention. Although duties of beneficence may seem more clearly applicable to the maternal role than to other contexts, the nature and boundaries
of maternal duties of beneficence are by no means understood. Among feminist scholars and other proponents of an ethics of care, there is a growing literature on the meaning of mothering and the moral dimensions of familial bonds. \(^3\) Still, many questions remain unanswered. Perhaps most fundamentally, how are we to understand commitment, self-effacement, and ultimately love in the context of parenting when what is considered by some to be heroic self-sacrifice on the part of a mother is considered by others to be nothing more than a standard instance of good mothering?

It is at this juncture that gender differences potentially loom large. At least for the foreseeable future, it is likely that many genetic interventions of benefit to prospective children will have to be delivered through the bodies of their pregnant mothers. How does bodily integrity and personal physical risk alter the dynamic, in moral terms, of the mother-child or parent-child relationship? My own view is that, if the stakes for the child are high enough, parents—both mothers and fathers—ought to accept some level of pain and physical risk to aid their child. If, for example, a father refused to be a kidney donor for his child when his kidney was clearly the child’s best chance for survival then, barring mitigating circumstances, that father would be morally beneath contempt. Similarly, if fetal surgery could spare a prospective child severe disability or illness, then (again, barring mitigating circumstances) a pregnant woman’s refusal of the surgery would be morally reprehensible.

Having said that, it should be emphasized that whether and to what extent mothers should, in a particular context, take actions that benefit their children is a separate inquiry from whether and to what extent state or professional action should encourage or compel pregnant women to behave accordingly. That is, from the finding that a woman would be morally wrong in refusing a genetic intervention that would significantly benefit her prospective child, it does not follow that the state would be right in compelling that pregnant woman to have the intervention, or that a health professional would be right in manipulating the woman into accepting the intervention. Such questions of public policy must take into account considerations external to the maternal-child relationship. The oppressive his-
tory of restrictions on the medical decisions of women, espe­
cially pregnant women, and the destructive effects on women
of social values and policies that view us dominantly as vessels
for protecting the unborn loom large in any discussion of co­
ercive or manipulative public policies. Indeed, it is at the level
of public policy, and not personal morality, that historical and
social differences between women and men may in the end be
the most morally relevant.

Conclusion

Although a full account of the moral dimensions of mothering
has yet to be developed, any plausible analysis would likely sup­
port the position that pregnant women ought to use reproduc­
tive genetic technology if the technology results in interven­
tions that could prevent or reduce significant illness or disability
in the child after birth. The moral justification for using such
technology in the absence of therapy for the child must rest
on considerations external to the relationship of the mother to
the prospective child—including, for example, commitments
to existing children, other family members, or oneself. In both
private and public discourse, it is important that we be honest
about our reasons for considering and justifying reproductive
 genetic testing. When a mother of normal intelligence prevents
the birth of a child with Down syndrome, or when a deaf
mother prevents the birth of a hearing child, they may be le­
gitimately furthering their own interests or those of others in
their family or community. They cannot plausibly claim their
action is in the best interest of the child who as a consequence
will never be born.

NOTES

1. Much of this analysis applies as well to prospective fathers who, for
example, may be called upon to undergo carrier testing in a reproduc­
tive context.
2. Both Steinbock (1992) and Arras (1990) have developed arguments de­
fending less stringent criteria for determining when it is in the interests
of a child (who would be born) to terminate a pregnancy.


