

PERFECT MOTHERS, PERFECT BABIES: AN EXAMINATION OF THE ETHICS OF FETAL TREATMENTS

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Synopsis — Medical technology often is employed to reinforce and sanction existing social roles. In this context, society's acceptance of fetal surgery sanctions women in their role as gestators and enforces their social obligation to bear healthy babies. Social norms place a negative value on babies with certain congenital conditions and view the birth of an impaired child as a tragedy. The use of fetal surgery in conjunction with selective abortion is consistent with a "perfectionist" ethic in modern medicine that regards physical and mental health as the ultimate good. An alternative ethic upholds the sovereignty of the individual woman in decisions involving her body during pregnancy.

INTRODUCTION

Modern medicine has become increasingly more vigorous in its efforts to intervene in the process of conception, gestation, and birth. Society is fascinated by advances in medical and surgical science because this technology extends power over human life at its earliest conception. However, scientists themselves may be unable to address the social and ethical implications of this new knowledge or the more general question of the impact of technology on health care policy (Kranzberg, 1984). Scientific research often proceeds in a policy vacuum defined minimally by restrictions on the use of human subjects in biomedical research, and the funding priorities of public and private agencies. Formal exploration of the consequences of new technologies is often withheld until the techniques are actually applied in human situations. Informal social norms and conventions are often employed to determine when and how new technologies should be employed. The interim between the discovery of new and experimental technologies and their incorporation into more routine medical practice is prey to confusion born from the application of normative standards that are inadequate to meet the moral choices generated by new technology.

Fetal surgery is a very new medical technology with serious implications for the medical control of women who are pregnant. This article explores two aspects of social expectations concerning pregnancy that define the normative background for the use of this technology. The first outlines social norms relevant to gestation that define pregnancy as a social role. The second concerns societal expectations for the physical status of new-borns and the social definition of disability as tragic. My purpose is to describe the basic dilemmas arising from the extension of medical technology in the process of reproduction and the ways in which societal expectations for women and children are most likely to be employed in the application of medical treatment of the fetus.

The current ethical debate over fetal intervention has focused attention on the fetus. The purpose of fetal surgery is to control the process of gestation and birth so as to increase the likelihood of the birth of only babies who fit socially prescribed expectations regarding their physical and mental condition. Taken in this regard, the control of pregnant women is an indirect consequence of this technology rather than a direct expression of modern medicine's explicit desire to control women. The distinction between the desire to control the individual (a pregnant woman) and the need to control a physical process and its outcome (gestation and birth) may at first glance seem to be gratuitous. Nevertheless,

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it is an important distinction made implicitly in many of the ethical arguments raised within the medical community in support of fetal intervention. The fetus is the object of ethical concern in the debate over fetal treatments. This has the effect of defining an ethical contingency for the rights of women known to be carrying an unborn but potentially viable fetus. From the perspective of modern neonatology, the woman's body becomes a conduit for the delivery of a newborn infant who should fit a general set of expectations. The subjugation of women in modern obstetrics becomes an essential expedient in the process of gestation and birth rather than a direct objective of patriarchal control. This attitude toward pregnant women reinforces the apprehension of their bodies as biological vehicles for the production of children. Women become means to an end. This has the effect of creating a perceptual and semantic barrier to discourse that makes the legitimate claims of women difficult to define and, once defined, difficult to defend.

PREGNANCY AS A SOCIAL ROLE

Although it is customary to consider pregnancy as a physical condition, some of the current controversy over fetal intervention may be more readily understood if we consider the social position of the pregnant person. "Being pregnant" becomes a social role, defined by a set of socially generated expectations for behavior.

Medical technology is generally used in a fashion which reinforces social expectations and obligations. In the case of technology related to birth, the application of surgical procedures to the fetus appears to be employed in a manner which reinforces two sets of social expectations. The first is the expectation that women commit themselves to the

role of "gestator" in late pregnancy (Lorber, 1987). The second is the expectation that only healthy babies should be born. I will first briefly examine social expectations for the gestator role of pregnant women.

The first social expectation for a woman in the gestator role obliges her to carry the fetus until it is born or dies in the womb. The pregnant woman is expected to treat her body in such a way as to promote the maximum health and well-being of the fetus she carries. Her diet, exercise, use of drugs, and psychosocial state are monitored for their effect on the fetus. Although her own well-being is not entirely subsumed under that of the fetus, it is accorded less emphasis. She is enjoined against risking her own health not because it may be detrimental to her but because it may have detrimental effects on the fetus.

Pregnant women are always encouraged, and sometimes compelled, to sacrifice their own comfort for the good of the baby. Many women voluntarily restrict their use of alcohol and other drugs in the interest of their own health and that of their fetus. They usually receive the support of the medical community and their own families in these efforts. The attitude toward maternal health may be best expressed by the adage, "Healthy mothers make healthy babies." The health of the mother is not an end in itself but a means to obtain healthy children.

This expectation also implies that the production of a healthy child is an individual obligation and that the actions of the particular woman are the primary determiners of the health status of the child. Other social forces beyond the control of the individual pregnant woman are underplayed as primary causes of poor health of the fetus. Factors such as poverty, limited access to prenatal care, or physical abuse by a spouse play less of a role in the collective accountability for fetal neglect.

A recent advertising campaign in New York City defined low-birth-weight

infants in terms of maternal failure. The ad consisted of a poster showing two footprints of what appeared to be the right feet of separate new-borns. One foot was larger and implied a child of normal weight for birth. The second was much smaller, suggesting an infant who was below normal weight at birth. The caption read: "Which baby's mother took drugs during her pregnancy?" As Katz Rothman has cogently pointed out, the caption could have just as easily read: "Which baby's mother tried to support herself on welfare?" or "which baby's mother was physically abused during her pregnancy?" (Katz Rothman, 1987). The impact of such public advertisements is consistent with the common sense understanding that the outcome of pregnancy is the personal responsibility of the individual mother and that poor outcomes must be seen as reflections of her own personal failure and neglect of duty.

The second set of norms relevant to the manipulation of human gestation define expectations for the birth of a child who is not healthy. Physical and/or mental disability when it occurs in any human being is viewed as a tragedy resulting from a loss of function. The judgement of loss is based on expectations for normal physical and mental abilities that are heavily weighted by the evaluations of physicians. Efforts to diagnose and intervene in the gestational process when certain fetal conditions are suspected enhance societal values regarding able-bodied children and the obligation of women to do everything they can to guarantee that their children will be healthy at birth. Barring correction of congenital conditions, physicians often encourage women to abort. In fact, abortion of a fetus with a congenital condition in late pregnancy has been upheld by courts in the United States. Abortion in the face of known or suspected fetal conditions is a preventive strategy whereby one "treats" disability by terminating any pregnancy likely to

result in a child with physical or mental impairments. Fetal surgery is developing as a medical alternative to abortion for the prevention of disabilities in children.

FROM FETAL PATIENT TO UNBORN CHILD CONSTRUCTION OF A SOCIAL OBJECT

Fetal surgery is the technique whereby anatomical impairments detected prior to birth are subjected to surgical intervention. Although most congenital conditions are best treated after birth, many fetal impairments can be diagnosed in the womb. The list of fetal impairments currently subject to surgical treatment before birth include hydro-cephalus, congenital diaphragmatic hernia, and obstruction of the urinary tract. By current knowledge, 22 congenital conditions are subject to diagnosis and treatment prior to birth. Scientific advances in the field, coupled with the development of refined surgical techniques, promise to expand the list before the close of this century (Harrison, Golby, and Filly, 1984).

In the context of medical care, the relationship of health care professionals to pregnant women changes with the development of effective fetal therapies. The ability to detect fetal movements, visualize the fetus in the womb, monitor heart beat and metabolic function, diagnose, and treat fetal conditions makes the fetus a well-defined element in the physician-patient relationship. Although it has been customary in obstetrics to consider both mother and fetus as patients, the mother has been the primary subject of care. Decisions to initiate or withhold treatments have customarily been weighted in favor of the well-being of the mother.

The development of medical and surgical techniques for prenatal intervention presents difficulties in decisions that involve significant risk to both the mother and the fetus. The availability of these techniques may tip

the balance of medical interest in favor of the fetus. The interest of the pregnant woman and the physician may not be antithetical in many cases of fetal intervention. Pregnant women are often willing to sacrifice personal comfort and safety in order to assure the health of their fetuses. However, we should be wary of any decision that compels such behavior on the part of pregnant women.

Furthermore, although medical professionals may be the most intimate observers of the fetus, the mother and other family members also develop a more explicit relationship with the fetus as a secondary consequence of such techniques. Parents and other family members may also invest in the process of pregnancy. This social investment in the fetus makes it a social object, but its presence still does not overshadow the social existence of the woman who sustains its life. Whether such action is enforced by formal laws or informal social expectations, forced intervention in pregnancy is the exercise of physical power over women and should be examined in those terms (Chavkin, 1982). The heated debate over the rights of women to control when or whether they will bear children has direct implications for the use of fetal intervention. In the case of fetal surgery, a great deal of activity in the law and in health care policy has clear implications for the use of these techniques. For example, the extension of equal protection rights to the fetus prior to birth implies that the fetus is a legal entity with some limited rights to due process and protection from harm, as well as the potential right to sue for malpractice in the event of survival with impairments after birth (Shaw, 1984).

In the wake of *Roe v. Wade*, the courts have upheld the right of pregnant women to terminate their pregnancies in the first trimester but also supported the right of states to regulate obstetrical procedures affecting the fetus (Lenow, 1983). The Supreme Court's decision endorsed a limited right for women to control their

reproductive potential – a right bounded by the interests of the state in the protection of human life and the administration of medical treatments. The status of the fetus falls short of full personhood under current interpretations of the abortion decision. However, there is legal and medical precedent that casts fetal rights in the language of child abuse and neglect (Kaufmann and Williams, 1985). Such a view permits the State to override the rights of parents in the interests of protecting the child from harm; but they also define a dimension of public duty for pregnant women – a dimension that was heretofore considered a matter of private concern and thereby exempt from regulation and control by the State (Hubbard, 1982; Lynn, 1982; Robertson, 1983).

The creation of laws that specify legal sanctions for “fetal abuse” reflect a common sense understanding of pregnancy as a personal obligation that the pregnant woman incurs within society. This implies that for the period of gestation, the pregnant woman is not only rewarded for foregoing her own comfort and health for the benefit of the unborn fetus; self-abnegation is expected as part of her maternal duty. In this context, medical technology relevant to fetal treatment affords the opportunity for society to do a more thorough job of monitoring her performance in the gestator's role and correcting deficits at the expense of her own bodily integrity.

THE CONSEQUENCES OF A TRAGIC VIEW OF DISABILITY

The live birth of a fetus with a congenital condition is unwelcomed, and fetal surgery is viewed as a means for preventing disabilities in neonates (Harrison et al., 1984). Physicians on the forefront of this technology have argued for careful screening of cases before attempting fetal intervention. Many in the medical community are reluctant to

employ extreme treatments that preserve the life of a fetus with a congenital condition.

This position raises significant questions regarding the social value of disabled children and adults. The reservations raised by many physicians over the use of fetal interventions to assure the live birth of a fetus that may have a congenital condition is based on a negative view of disability. There is a contradiction in the ethics of medicine that supports intervention to restore the health of the fetus in one instance, and supports the termination of fetal life if it appears to have a noncorrectable condition. However, these seemingly contradictory ethical positions are both consistent with the social expectation that physical health is an ultimate human good and a precondition for participation in the life of the social group.

The popular press views the birth of a handicapped or disabled child as macabre and tragic – a view echoed in the attitudes of many people. Society tends to view disabled individuals as burdens to their families, themselves, and to society. The image of disability as both tragic and burdensome is reinforced by the willingness of the medical community to extend abortion services to women carrying fetuses “at risk” for such conditions as neural tube defects or Down’s syndrome.

Most physicians are aware of limitations in the sensitivity, specificity, and predictive power of fetal diagnosis that make the outcome of pregnancy indeterminant. Nevertheless, pregnant women receive a clear message concerning their duty to carry healthy babies – and only healthy babies – to term. The problem is that most lay persons in the patient role have limited access to information and limited freedom to make a decision about consent or refusal of medical treatment. Information crucial to the decision to use fetal surgery is controlled by physicians.

In addition, both the standards for

determining what is normal in the fetus as well as the technology used to treat its impairment or terminate gestation are medical. The medical profession claims the power to both define the normative criteria for fetal function and apply technology to change that function.

The point I wish to make here is that any commitment to the fetus is a moral choice that physicians are increasingly making independently of pregnant women. This is an ethical position that has far reaching consequences for the lives of women and children. It justifies medical decisions to override a woman’s refusal of medical treatment as well as the physician’s decision to encourage the abortion of an impaired fetus. An emergent policy in favor of a medical definition of “normal” is consistent with social norms permitting society to invest selectively in the procreation of individuals with characteristics deemed desirable by politically dominant groups (Hartman, 1987).

SOCIAL JUSTICE IN GESTATION AND BIRTH

In this discussion, I have argued that fetal surgery is consistent with a socially defined role of women as gestators in addition to negative social norms regarding disabilities. These two sets of expectations define a social obligation on the part of pregnant women to comply with the judgment of medical experts in the handling of birth. Fetal surgery in the later stages of gestation is employed to construct an image of the fetus, first as a patient in medical treatment, and second as a potential child subject to protection from harm. A commitment to in-utero detection and treatment of anatomical impairment has the effect of limiting the freedom of women in order to uphold medically defined norms for gestation and birth. Fetal surgery is likely to develop into a popular form of treatment primarily because it fits well within the existing social institutions concerning the obligations of pregnant

women and the presumptively negative views of disability.

There is ample precedent in the law establishing the judicial right to limit the freedom of one individual in the interest of preserving the rights of another who is regarded as more vulnerable. Most societies set limits on personal freedom in sanctioning collectively shared norms. The issue in fetal surgery is the potential obligation of a pregnant woman to submit to medical procedures that may cause her discomfort or actual harm in the interest of decreasing the risk of harm to an unborn fetus. The medical view of birth in-stills increasing value in the fetus as gestation proceeds. Such an investment in the fetus is one basis for undermining the integrity of pregnant women, particularly in the later stages of pregnancy. As a consequence, the value of the life and physical integrity of the woman becomes contingent on the fulfillment of her role as gestator. Women are asked to sacrifice their own wellbeing in the interest of *potential* human life. Considerations of the *actual* lives of these women appear to be given less weight.

In my view, the construction of a socially defined contingency that evaluates the social worth of the mother with respect to the well-being of her fetus is wrong for three reasons. First, it requires social consensus on the humanity of the fetus prior to birth. Most cases of forced fetal intervention have been decided based on laws protecting children from abuse and neglect. Such decisions are possible only through judicial acknowledgment that the fetus is a child prior to birth, however, there is no judicial consensus on this point. It appears that the status of the fetus is a function of the attitudes of those around it, most importantly pregnant women and physicians who treat them. In cases where both the woman and her attending physicians agree, treatment decisions are not morally problematic. However, when

there is disagreement, the decision to initiate or withhold treatment should be made with a clear bias favoring those who will bear the most direct consequences for the decision. In the case of pregnancy and childbirth, the pregnant woman is the one most directly affected by the consequences of birth, and her decision should prevail in cases of conflict.

A second reason for control of fetal surgery lies in the need to protect the autonomy of patients in the context of medical treatment. Technology applied to the birth process should function as a service offered to women at their discretion. Any intervention should be guided by a primary interest in preserving the integrity of the woman. This includes her desire to continue pregnancy and correct fetal conditions if she chooses. No medical procedure should be forced on a patient solely because her opinion differs from those of physicians. Medical technology works best when it extends and supports individuals choice.

The third and final aspect I would like to consider involves the notion of justice. Rawls has argued that the principles of justice that are embedded in any free society include the view of human beings as rational selectors of their own ends and means. This position is a priori to independently determined conceptions of what is good for them. Each person is her own sovereign and equal and should make decisions based on a personal understanding of what is best for that individual. People should not have their opinions molded by indoctrination or limited access to information. In cases where reasonable people are likely to differ, the only recourse of a just society rests with the sovereignty of the individual (Rawls, 1971; Scanlon, 1973). According to this view, the fairness of a social institution, including medicine, can be determined by each member of the institution based on the contributions it makes to each individual's good as assessed from that individual's own point of view.

THE ETHICS OF PERFECTION

One may hold principles of individual justice and still argue that fetal surgery is justified even when the pregnant woman objects because such intervention protects the interest of the future child. One may argue that the potential child wants to live and do so without disabilities.

It may be reasonable for a third party – a court-appointed guardian, for example – to decide whether the risk of undergoing surgery is warranted given the potential benefit of life as an able-bodied person. But what is the position of the guardian in cases of non-correctable congenital conditions? No rational person can evaluate the condition of its own nonexistence. It is logically absurd to envision a rational being deciding that it is better for itself not to exist. Such a position is taken for the benefit of others, not for the individual. Society may decide that it is better not to nurture or protect the lives of individuals who do not offer things that the society values, but a person cannot reasonably decide that it is in his or her own best interests to not exist.

A third party cannot take the position of the unborn fetus and make a reasonable determination that the unborn fetus would choose death over life, whether that life is lived with or without a disability. From the position of society, the argument in favor of abortion might be that no reasonable person would want to bear and raise a disabled child, and that disability is a burden to the family and to the social group. However, an individual in the position of the fetus cannot argue that a reasonable person in its position would choose nonexistence over life with a disability. Such a decision is made for the convenience of the social group, not the good of the fetus.

Decisions supporting mandatory fetal treatment or selective abortion reflect an ideal of human perfection that is defined, nurtured, and preserved through medical technology. Again, I turn to Rawls in his discussion of “perfectionism” in human

societies. According to Rawls, perfectionist theories are those that direct the social group to enforce duties and obligations on individuals so as to achieve human excellence in art, science, and culture. Perfectionist theories are similar to religious dogmas in that they share a common “teleological structure” (Scanlon, 1973, p. 172). Such theories establish the value of a particular goal and then judge the worth of social institutions in terms of their ability to advance society toward this goal.

Among Westernized cultures in the late twentieth century, the medical profession has emerged as the social institution dedicated to the advancement of human mental and physical perfection. There is a need to examine critically the value of such a goal in human society. Physicians who take the ethical position that physical and mental health is the ultimate human good manifest a perfectionist ethic that is structurally similar to religious principles.

Insofar as medicine as a social institution defines and enforces standards for physical and mental perfection, its ethical positions and its opinions on essential aspects of social policy require us to examine it as moral dogma. Physical and mental health is not an ultimate good, but one quality among many that human beings possess to varying degrees. Other, equally compelling, qualities of life – including the capacity for human attachment and understanding – exist independently of health and may coexist with states of disease and disability. There is no good reason to weigh the value of health as an ultimate human good, especially when other notions of good may also be held by reasonable men and women.

CONCLUSIONS

Casting individual women as primary determiners of the course and outcomes of their pregnancies is consistent with justice because it places the individual in a

sovereign position as decision maker in cases where reasonable people differ in their opinions about the desired course and outcome of pregnancy. Second, it gives a primary weight to the decision of the individual who is asked to bear the most personal and severe consequences for the decision. Third, it avoids the a priori imposition of perfectionist ethical principles supported by an institution that is devoted to the elimination of disease as the ultimate good. In making this point, I do not wish to suggest that poor health is a “good thing” or that suffering should be an essential part of any human life. Rather, the effort to remove disease from the human experience must be regarded as one of many human enterprises, and the desirability of that goal should be weighed in the context of other notions of “good.”

The forced application of surgical procedures upon a pregnant woman in order to treat the unborn fetus is a unique circumstance, not substantiated by existing laws regarding parental duties to children. A mother cannot be forced by law to undergo surgical procedures to save the life of her child after its birth. Therefore, it seems that the laws that have been used to support judicial override of a competent woman’s refusal of fetal treatment derive from social expectations that support the subordination of women in their childbearing roles and a collective wish to deny disability as a viable aspect of human experience.

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