Debating the Genetics Utopia

Can therapeutic cloning exist to serve the good of health?

Mark Repenshek

> *All material reality is simply plastic to be used, dominated and ultimately shaped by human freedom. Thus the fundamental purpose of the entire physical universe, including human biological nature, is to serve as the instrument for human purposes. The body is subordinated to the spiritual aspect of humanity, and humans view themselves as possessing an unrestricted right to dominate and shape not only the body but also its genetic heritage* (Callahan, 1972).

This quotation takes on an interesting dynamic in the context of the current genomic revolution in medicine. Although some of the critiques of the Human Genome Project (HGP) tend to focus on who owns our genetic information (Annas, 1993; Everett, 2003; Moore, 2000) or whether an insurance company has a right to information provided by genetic screenings (ASHG Ad Hoc Committee on Insurance Issue in Genetic Testing, 1995; Gostin, 1994; juengst, 1991b, Hudson, 1995), this is not where the real ethical and theological action is with respect to the ongoing revolution in genetics. The action lies in understanding the concepts of health, disease and normality. It is here where the genomics revolution will fundamentally change our understanding of these concepts in a way we have rarely seen in the history of science (Caplan, 1992).

Julie O'Rourke

This paper seeks to understand the purpose of medicine in a genomics context through an ethical analysis of the meaning of service. This essay will argue that the notion of serving the good of health necessarily means refocusing on the very technology that claims to do just that. Such a focus will force humanity to examine what kind of people we are and how best to serve the good of health. A profound understanding of how best to serve the good of health may ultimately require an acceptance of our imperfections, lest we sacrifice moral concern for the means used to achieve that end.

SERVING THE GOOD OF HEALTH

The purpose of medicine has long existed to serve the good of health-that is, the complex of functional, goal-directed psychophysical systems. Medicine has traditionally combated disorders in these systems by prevention, treatment or palliation. By definition then, medicine concerns itself with the functional defects that limit the ability of human persons to achieve health (Holt, 2001; Pellegrino and Thomasma, 1981; Trotter, 1997). More broadly construed, the purpose of medicine is to address functional defects on a foundational level in order to restore human teleologies (Pelligrino and Thomasma, 1988). The ability of medicine to restore these teleologies is presently limited by an inability to truly cure disease-that is, the correction of gene-based functional defects. As such, the purpose of medicine is never fully realized. Genomics may fundamentally change that notion, by offering medicine the ability to truly cure disease-that is, correction of the gene-based defects (Hoedemaekers and Ten-Have, 1999). However, the ethical question of how genomics ought to fundamentally change our notion of health rests on the assumption that genomics, like medicine, will exist to serve the good of health. Hence, any ethical analysis of genomics first demands a clear understanding of what it means to serve the good of health.

In American medicine, there is ambiguity surrounding the aims, goals, definition or purposes of the healing profession. Although the task of the health care provider is clear-reverse pathological processes, and if cure is not possible, provide means of palliation-the end toward which those actions are directed is often unclear. This is due in large part to the rule: ‘yield in the face of autonomy’ (Childress, 1982). In clinical situations where doubt exists, adherence to this principle necessarily minimizes the need to discuss the more general questions concerning the aims and goals of the intervention (Pellegrino and Thomasma, 1988; Faber-Langedoen, 1992).

In research situations where uncertainty exists about what to do with new knowledge gained from experimentation, researchers may simply acquire knowledge without concern for application. In the case of the HGP, where the Ethical, Legal and Social Implications of genetics research (ELSI) project is the only incentive to examine conceptual foundations of health and disease, researchers may simply deny any controversial applications of their research. The clearest examples of this strategy are the promises that neither germline gene therapy nor reproductive cloning will be done (Walters, 1986; Anderson, 1994). Here, the promise to avoid offending societal mores is the simplest strategy to defuse worries about ethical issues related to a particular therapeutic intervention (NBAC, 1997; Brock, 2001). However, such a promise also avoids necessary discourse on how to fit new genetic knowledge into existing discourse on disease, health and normality. Discussions of this sort are necessary if genomics is to serve the end that justifies pursuing the research.

THE PURPOSE OF MEDICINE AND ITS OBLIGATION TO SERVE THE GOOD OF HEALTH

This paper now moves beyond focusing upon the legitimacy of particular genomic therapeutic interventions to argue that medicine has a prima facie obligation to pursue and employ appropriate genetic interventions. The focus here is on: (a) the duty to utilize genomic interventions grounded in the nature of medicine; and (b) the implications of that duty for the health needs of patients.

1. Genomic Interventions and the Nature of Medicine

Medicine pursues science in a value-biased manner. That is to say, medicine is interested in knowledge that seeks to secure its end of promoting human health (Chalmers, 1990). Science is a piece in the compendium of theories, experiments, and human interactions that makeup the «art» of medicine. It is a means to an end. Science provides reasons for accepting the empirical data that describes the nature of the world. Medicine, on the other hand, does not have such an «epistemic criterion.» Rather, the success of medicine is evaluated with respect to its aim (Chalmers, 1990; Munson and Davis, 1992). Hence, science is viewed as an essential component of contemporary medicine's goal to promote the health of patients.

In seeking to pursue health, medicine can be described as the attempt to control factors that affect health. Science is important to this end. Knowledge gained from science leads to evidence that suggests ways to control. Clinical experience then provides the evidence of practical success validating the empirical rules.

The medical profession has long recognized it as their responsibility to treat, and if possible, prevent illness and infectious disease. The means used to achieve this aim are continually modified to maintain safety and efficacy. Conversely, the medical profession recognizes the responsibility to not withhold treatment that is known to offer treatment or prevent pathology (Juengst, 1991a).

A consequence of medicine's attempt to control is that it develops a self-imposed therapeutic obligation. That is, fundamental to medicine is a prima facie obligation to treat those who seek the means to achieve a degree of health of which they are capable. This obligation can extend beyond traditional paradigms of treatment to prevent the occurrence of disease. Hence, if medicine aims to promote human health by exercising control over a disease, and elimination of disease is the most effective form of control, then elimination of disease is the ultimate aim of medicine.

2. Implications of the duty to utilize genomic interventions for the health of patients

The application of the principle that the medical profession is to act primarily in the interests of the patient to relieve unnecessary suffering and eliminate disease can be extended to those at risk for serious genetic disease. Therapeutic cloning promises a means of controlling disease. Furthermore, its ability to intervene in the genetic basis of disease offers elimination of disease. Given medicine's ultimate aim to eliminate disease, therapeutic cloning then gives medicine a means by which to achieve that end. Here, one could argue therapeutic cloning is a clinical practice that medicine is obligated to pursue insofar as its explicit aim is to promote human health and eliminate disease. Hence, where a genetic anomaly exists and therapeutic cloning is available, the possibility to cure genetic disease is a reality (Cohen, 1998).

This conclusion is troubling. Here, a legitimate justification for therapeutic cloning is made without recourse to an ethical analysis of the means used. In other words, based solely on the legitimate principle of relieving human suffering and eliminating gene-based disease, therapeutic cloning as a means to that end seems justified. Yet, within the context of this realizable end, such therapeutic promise also avoids necessary discourse on the new genetic knowledge itself. It seems therefore, that a therapeutic's ability to serve the good of health alone cannot be the only ethical «litmus test» to justify its use in the new genomics revolution in medicine. A greater analysis of therapeutic cloning itself is therefore necessary.

A RELEVANT CONTEXT: THE ETHICAL DILEMMA OF THERAPEUTIC CLONING AND ITS ABILITY TO SERVE THE GOOD OF HEALTH

Arguments for and against human cloning rest on the distinction between reproductive and therapeutic. This distinction is an effort to delineate a technology in service of two distinct ends: the first, to create genetically identical human persons, the other to create embryos that may yield stem cells which promise great medical benefit. The first is almost universally unacceptable (Forster and Ramsey, 2001; Moreno and London, 2001; NBAC, 1997; Tauer, 2001). The latter is more elusive (Magnus, 2001). Therapeutic cloning seeks to serve the good of health by providing a means to harvest stem cells in order to create a cultured cell line for the purposes of cell or tissue therapy. In order to justify therapeutic cloning however, the argument must ignore the very means by which the technology claims to be of service for future health benefit. That is, the willingness to cure the next generation's genetic anomalies - in order to serve the ultimate good of health - paradoxically implies a willingness to gamble with their well-being. Hence, therapeutic cloning, in an effort to serve the good of health, is in direct conflict with the moral disregard required to perfect the technique (Cohen, 2002).

Former President Clinton's National Bioethics Advisory Commission (NBAC) issued a key contribution to the debate on human cloning in 1997. In that report, the commission condemned «the attempt to create a child through somatic cell nuclear transfer (NBAC, 1997).» Interestingly the report avoids condemning experiments in cloning that fall short of the birth of the child (Kaveny, 1999). Here, it is evident that the report recognized the potential for great benefit promised by embryo research and did not want to prohibit outright such research efforts. In short, the commission leaves open the question of whether therapeutic cloning can serve the good of health.

NBAC's resolution to the debate neglected two key ethical questions: First, is such research on the early human embryo justified? Second, if such research is morally permissible in itself, should it be restricted because it will enable the perfection of techniques that will make inevitable the creation of a cloned child (Warnock, 2001)? Implicit in NBAC neglect is the claim that avoiding pain and suffering for the patient may be considered to be more morally significant than the moral status of the early embryo. Yet, such a conclusion is inadequate given the diversity of ethical issues NBAC did address related to therapeutic cloning specifically, and embryo disposal in general.

The basis of the NBAC prohibition on human cloning relied rather on the liberal harm principle. This principle, narrowly construed, holds that legal restrictions on human freedoms are justified only in order to prevent a high likelihood of tangible harm to identifiable individuals. However, as noted by many theologians testifying before the NBAC, once science can ensure that relatively little harm will come to children achieved through reproductive cloning, the NBAC's basis for the prohibition on human cloning will erode (Kaveny, 1999).

RETURNING TO THE NOTION OF «SERVING THE GOOD OF HEALTH»

For those who believe the HGP is of great value, accompanies the task of allaying fears concerning misapplication of the knowledge the project intends to create. Yet, when religious sects like the Raelians continue to strive to clone the first human being, ethical distinctions are blurred and fear runs amok. At the same time, however, when scientists who wish to pursue therapeutic cloning argue in its defense, careful use of language and clear articulation of the processes involved must be divulged honestly and pensively.

The greatest challenge to securing continued research into the human genome and its applications does not originate from concerns about privacy, confidentiality or coercive genetic testing (Caplan, 1992). Rather it is eugenics - manipulation of the human genome in order to improve or enhance the human condition. It is also eugenics, however, that begs we ask the important question: can genetics serve the good of health? It is only in answering this question that we deal with the fundamental questions of what constitutes disease, health and normality. Such questions will ultimately force humanity to examine its anthropology: that is, what we consider the normatively human to be. This is a far broader understanding of the means-end relationship. This understanding places the human person at the center of the ethical analysis by engaging the eugenics debate. It is an ethical analysis that understands that to change the body, is to change the person (Keenan, 2001). That is the locus of the issue. Only then can we understand what it means to sacrifice the human embryo for the purpose of restoring health to the patient suffering from gene-based disease.

CAN THERAPEUTIC CLONING SERVE THE GOOD OF HEALTH?

Some believe that a ban on human cloning ought ban all forms regardless of the distinction between therapeutic and reproductive. While others feel that more research must be done before we can move past speculation and discuss the facts associated with therapeutic cloning (Brock, 2001; Gillon, 2001). Regardless of one's viewpoint, there is no slope that leads inexorably from therapeutic cloning intended to benefit person suffering from genetic disease and the creation of eugenically driven social policies negating any moral status to the human embryo.

There is some wisdom in foregoing public policy on therapeutic cloning in light of the current political climate. But to do so, makes no sense conceptually or ethically (Klotzko, ed, 2001). The proper way to handle legitimate concerns about the dangers and potential abuses of therapeutic cloning is to forthrightly examine what are and are not appropriate goals that serve the good of health, broadly construed. Eric Cohen poignantly states, «It would be silly to deny the value of health. Health is a blessing, not to be trivialized by the healthy (Cohen, 2002).» If health is necessary for the human person to flourish, and human flourishing is what we seek, then discourse is necessary on how therapeutic cloning can serve that good without violating the foundation upon which health is sought. In other words, therapeutic cloning may ultimately serve the good of health, ethically and morally, if we truly understand what the use of those terms mean.

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Back to current electronic table of contents