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Item Type	Essay
Publisher	Centro de Publicaciones Académicas, Facultad de Artes y Ciencias, Universidad de Puerto Rico en Mayagüez
Download date	2025-03-16 23:29:21
Link to Item	https://hdl.handle.net/20.500.11801/3184

THE CHALLENGE OF THE HUMAN GENOME PROJECT TO THE ETHIC OF NEUTRALITY IN THE PHYSICIAN-PATIENT ENCOUNTER

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INTRODUCTION

The physician-patient relationship is often characterized as *FIDUCIARY*. This relation is to be one of trust particularly on the part of patients in regard to a professional considered reliable, competent and duty-bound to respect the person as well as his/her best interest. That is, the professional is bound to seek the patients' *best interest* (Principle of Beneficence?, as well as to accept the patients' self-determination or autonomy (Principle of Respect of the Person). The patient's autonomy need not entail an individualistic and confrontational defense of rights against a well-intended professional. Thus, a delicate balance between the Principle of Beneficence and the Principle of Respect of Person is constitutive of the physician-patient encounter. These principles ought not, at least in theory, be in conflict. But in practice these principles come under challenges and function in reciprocal tension. The *Human Genome Project* (H.G.P.) presents such a challenge.

The H.G.P.—as well as the genetic screening and therapy such a complex and expensive scientific research entails—challenges the patients' self determination (autonomy) as well as best interest and therefore can undermine the basic trust in the relationship. The H.G.P. facilitates a medical practice oriented toward a *prediction* of illness and disease or an affinity and disposition toward them. In view of this predictive role of the professional we must rethink the meanings *autonomy* and *best interest* have within clinical ethics but also search for its foundation in philosophical theory.

As a point of departure let us consider a non-directive value neutral approach which claims to provide the patient the genetic facts as objectively as possible and to refrain from giving recommendations so as to promote patient's autonomy. This approach can be subjected to criticism. First, the factual data in genetics is at present sufficiently ambiguous, both in definition and implications, so as to be of dubious objectivity. Second, genetic information is not yet fully integrated in the medical expertise so as to secure or serve as evidence of professional competence in medical service. Third, since genetic makeup is interpreted as a component of one's identity, harboring the seeds of one's mental and physical integrity or deterioration and death, its existential dimension must not be underestimated, but brought into awareness as a pre-condition for responsible freedom. Fourth, providing genetic facts does not constitute a medical act of mere scientific nature but an exercise of medical care inclusive of interpersonal and social factors.

From the above critical observations one may conclude that the value-neutral approach in genetic-oriented medicine is deceptive in intent and unable to promote authentic autonomy (i.e. both free and responsible). Factual data in genetic-oriented medicine can not be delivered in abstraction from values. A value-neutral position might entail a view of the physician as a technician inclined to respond to a strong sense of autonomy on the part of a patient who not only selects and chooses, but also demands a medical service on the basis of individual preference.

This sense of autonomy must also come under criticism. Though clinical genetic information is about an individual it also is about a generation (past-present-future family). Therefore a strong individualism does not seem appropriate. I suggest to dislodge the concept of autonomy from individualistic egocentrism and to recognize its possible communitarian orientation. In U.S.A. the President's *Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research* asserts no strong positive rights inherent in autonomy. In its study of informed consent—Making Health Care Decision (page 3)—the President's Commission concludes: "(Although) adults are entitled to accept or reject health care interventions on the basis of their own personal values and in furtherance of their own personal goals, nonetheless patient choice is not absolute." The patient is not entitled to insist on services that are not within "the bounds of acceptable practice," continues the commission's conclusion. In many respects the emergent technology of predictive ge-

netic tests as the basis for personal life choices is fluid. While it is entirely proper to make these tests available, it remains at the discretion of the professional because the exact parameters of acceptable practice (reliability, sensitivity-selectivity, and indication) are often still in a formative stage, and professionals themselves remain divided on precise guidelines.

In *Screening and Counseling for Genetic Conditions* (also from the President's Commission) the emphasis on autonomy is intended to argue against measures that would call for compulsory screening or limit individuals options by curtailing genetic services. It also acknowledges instances in which disclosure of potentially harmful information might compromise other values. Thus, (page 59) "genetic counselors and providers must decide whether such incidental information should be revealed to the individuals."

While stating that genetic testing and counseling be provided "to an individual who desires information as an aid in making personal medical and reproductive choices (Section 6, page 54) the Commission limits the force of autonomy to a presumption in favor of disclosure (of unfavorable information) which the clinician is free to override.

However, even the presumption in favor of autonomy expressed in endorsing the promotion of patient choices, on analysis, appears rooted in the recognition that in personal reproductive and medical choices the information is essential and instrumental to avoiding specific outcomes that are undesirable because they represent harms or serious disadvantages (for example, conception or birth of offspring with genetically-related illness, or onset or worsening of a condition preventable by timely detection and intervention).

Allow me to quote two articles delineating the limits of autonomy in imposing obligations on physicians. Regarding a justification to override a patient's refusal of treatment F. Chervenak and L. McCullough point out: "Patients do not have a positive ethical right to obligate physicians to practice medicine in ways that are patently inconsistent with the most reliable clinical judgment" ("Justified limits in refusing intervention." *Hastings Center Report* 21, 2 (1991) 12-18). Schneiderman, Jecker, and Jonsen argue that, with some compassionate exceptions, "physicians are required only to provide medical benefits to patients. Physicians are permitted, but not obligated, to offer other, non-medical benefits."

Contemporary bioethics literature in general view autonomy as having a limited force. Rather, we may say autonomy needs to be

viewed in the context of the principle of respect for person, which in turn leads us to examine another aspect of the clinical situation: *best interest*. But with this term one can anticipate how respect for person must be complemented by the principle Of beneficence.

II

We have already indicated that research in genetic medicine has increased the physician's ability to predict whether individuals are at risk for particular diseases—often serious diseases with tragic human consequences. Physicians may clinically intervene before disease takes its toll or tailor their advice on diet and life-style to the individual. Nevertheless, often the prediction of a disease not only remains ambiguous as to its occurrence, but also often lacks a corresponding therapy or means for its prevention. In either case, determining the *best interest* of the patient is a most difficult balancing act—neither beneficence alone, for it might lead to active paternalism, nor respect of person with the strong emphasis on autonomy as just criticized.

Best interest of the patient is a complex notion to apply particularly given the ambiguous and multiphasetic character of clinical genetic information. Pellegrino and Thomasma suggest at least four components of beneficence as it pertains to patient's best interest inclusive of the subjective and objective dimensions of "interest" medical—good or affect, patient preference, good of the human as human, and the good of the last resort or spiritual, transcendent horizon, (E.D. Pellegrino & D, Thomasma. *For the Patients Good* (New York, Oxford University Press (1988. Page 35)—*Medical good* and genetic medicine—) Evidently the clinician is equipped to determine whether a test is technically possible. A clinician must then question the medical advisability of the test, its complexity, duration and financial burden. But it is also necessary for the clinician to consider if the participation of relatives is indicated so as to secure information that is reliable and precise. Grounds of exclusion of patients must also be clinically determined. In any case the medical good as a component of the patient's best interest—good for him/her—must represent, as far a possible, a responsive, respectful and supportive approach in the part of the clinician.

Patient Preference. Preference might reflect false hopes, spring from coercion or from psychological pressure or from inner compulsion. Perhaps uncertainty about one's genetic structure generates enough stress for the patient to demand tests, and possible preven-

tive measures. Discernment on the part of the physician and the art of persuasion to recommend what is a course of action attuned to the patient's preference but also in harmony with professional competence is difficult. Informed consent, as reasonable and responsible consent, includes incorporating autonomy or respect for patient's preference within a context of what the good of medicine, considering also the good for the particular patient. But this recommendation entails a broad conception of the *good as what ought* to be of interest. Here we refer to the good as it pertains to the full realization of what its means to be a person. For brevity I single out the main features that are generally considered distinctive capacities for being a person (basis for "reasonable standard" as criteria): consciousness, self-consciousness, reflection, self-determination, intersubjectivity, temporality, emotional refinement, aesthetic experience, technical abilities, and transcendence. In view of the last capacity a person seems receptive and longing for the "*good*" as an *ultimate criteria* or as some conception of the perfection/all good so often crystalized in religious consciousness. The consideration of the good in these two later senses requires both patient and doctor to engage in a dialogue about the meaning and quality of life, dignity of person; in short: discourse on values.

A critical question now forces itself on us: is a "best-interest" concern on the part of a physician equivalent to a duty of beneficence, inclusive of the four dimensions of the good? It seems a physician has an imperfect duty to promote the medical good of the patient, and perhaps a perfect duty to do so once the therapeutic relationship is constituted and if no one else is equally competent to serve the best interest of the patient. In the best of situations the medical good and the patient's preference coincide.

On the event that the patient rejects or disregards the medical good and affirms his/her preference (good as interest-right-needs) then one may consider if "justified paternalism" is ethically indicated. At least three conditions must be satisfied for beneficence as a duty to prevail—(1) defects, encumbrances, and limitations of a persons decision-making and acting; (2) the probability of harm to that person unless there is intervention; (3) proportionality, the probable benefit of intervention should outweigh the probable harm of non-intervention. It is not possible here to go into the intricate details on how to implement the duty of beneficence and its possible allowance of paternalistic intervention. Sufficient is to indicate that the Principle of Beneficence does not lead to hard, active, direct paternalism, but rather it functions in complementarity with the Principle of Respect

for Persons.

Before we turn to the other components of “best interest” let us mention a principle correlative to beneficence—i.e, “do no harm” (non maleficence). The avoidance of harm denominates a so-called perfect or kantian universal duty to be alert to possible adverse impacts on the patient. A “protectionist” mode of paternalism recognizes that some patients are not able or willing to assume responsibility and determination in regard to self welfare. The clinician must at least prevent and avoid the actual doing of the harm unless necessary for a basic degree of care. Of course, there must be an objective norm to determine the later. Fortunately what is not in the interest of a patient is easier to determine in precise terms than is to determine what is in the interest (in the sense of medical good and patient preference). But what is most problematic is to determine in universally acceptable mode what *ought* to be in the best interest of a patient—in the sense of the “good as the good of the person” and the “good of the last resort” (Pellegrino & Thomasma). A strong sense of beneficence as well as another mode of “avoiding harm” (Principle of Normaleficence)—“Proactive paternalism” inclined to raise individuals to a standard of rationality in decision making, presuppose the four senses of *best interest*. Pro-active paternalism promotes preventive health measures but also encourages patient’s adherence to a long-range emphasis upon health and well-being. Once more the Principles of Beneficence and Respect of Person interact. But the possibility of conflict between “medical good” and patient preference on the one hand and good of the person and transcendental good on the other remain at the center of this interaction.

III

We now address this conflict as it pertains not only to genetic medicine but to clinical ethics in contemporary practice. Considerations of the *best interest* with the implication of an *ought* as pertains to the good of the person and a transcendental dimension are highly problematic within our western culture at present. Our culture has been characterized as pluralistic, secular, liberal, and individualistic. The immediate implication is that basic definition of moral virtue, universal and necessary ethical principles or general agreement on what *ought* to be expected in communitary life are all subject to endless debates. The cultural atmosphere promotes a clinical ethics within the framework of a new conception of bioethics. I will now present this conception which I regard inadequate to the task of

clinical ethics and then offer some pertinent recommendations to lead ethics into its search for a foundational framework.

At present bioethics is not any more a branch of moral philosophy in its traditional speculative, deductive mode of abstract discourse. Bioethics is more interdisciplinary and benefits from the moral insights and concepts provided by law, sociology, psychology, religion and medical praxis among other sources of practical challenges. But the philosophical method remains central clarifying, organizing, and criticizing the assumptions, implications as well as basic criteria of each discipline that provides insights.

But bioethics seems more regulative than prescriptive. In this role ethics is more akin to law and oriented more toward public policy than to reflection on the good or in foundational questions pertaining to duty—the ought and ultimate responsibilities in life. The *procedure* on how to promote dialogue and reach consensus and implement strategies to guide behavior become paramount, while the substantial and essential component of values and ends for human action are addressed with reserve. Establishing individual interest and needs and promoting liberty as alternatives in choosing overshadow the very question on what constitutes a good life and what is the responsibility attached to the exercise of human freedom. Bioethics attention to procedures and rules do not reflect concern with moral obligation as inherent to moral consciousness.

Perhaps A. MacIntyre is correct when he claims that autonomy maybe a matter of last resort in a pluralistic society, where we cannot rely on each other to act in certain ways because we lack a common system of belief, values and principles. He adds we lack authority because we lack common traditions (MacIntyre—"Patients as Agents"—in *Philosophical Medical Ethics*. S. Spicker and H. Tristram Engelhardt-Boston: Reidel Pub. 1977, p. 210). Now it seems to me that precisely because of the central value recognized to autonomy it becomes imperative to pursue the ethical task if reflecting anew on *what* the Principle of Respect for Person and on *what* the good in its broad significance for the Principle of Beneficence entail. And precisely because each individual is expected to contribute to the ethical discourse, it becomes urgent to foster ethical sophistication at least in the professionals and leaders which even a democratic liberal system need in order to constitute a human society. In what follows I only single out some of the main components of this renewal of ethical reflection.

This reflection may not be a simple logical deduction of rules from an abstract compressed and unified system of principles to be

applied to concrete situations viewed as manifestations of the general categories. Our cultural pluralism seems to exclude such a model. But neither may it be an ethics of casuistic incorporation of concrete situations into paradigmatic samples established by inductive reasoning. The urgent need for a sense of the *ought* in moral experience will not be satisfied with this model either.

Thus while the deductive model might fail to attend to the individual complexity of the moral life, the casuistic model presupposes a moral intuition without a convincing foundation for moral obligation. Before we propose the main features for a third way of ethical reflection, let us recall the challenges from genetic medicine which lead to this presentation. Genetic medicine requires us to consider individual autonomy—self-determination on the part of the patient—but also a responsibility to assess and scrutinize values in a network of interpersonal relationships in search for a connate foundation in values. The moral significance of health, the philosophical basis of the integrity and dignity of the person as individual and in relationships, as well as the ultimate significance of life and its transnissian are issues in which neither science, technology or even socio-economical-political compromises are sufficient enlightenment.

My proposal entails a dialectic of reason and experience, that is, an effort of reason to draw sense and normative meaning from the implication and demands of human experience. We seek to respond to the moral significance of relationships or of the whole situation as is the very physician-patient encounter within the context of community. In attention to the legitimate claims of deductive theories we recognize the role of principles as explanatory and integrating and of reason's capacity to formulate coherent consistent theory. But principles—indeed, such as clinical ethics ordinarily used and here already presented (autonomy—beneficence—no-maleficence) are practical guidelines of human wisdom rather than rigid premises for strict deduction. Principles admit a necessary and universal conceptualization but in practice unfold in the course of human application admitting a plurality of aspects. That is, principles are to function as inspiration and convictions from within a self-disciplined rational inquiry and not as mere regulation and criteria from without the demands of the human condition. The contribution of reason in assessing and formulating the principles is a difficult and complex question in past-modern times. We speak here of reason as a human capacity to search critically—through doubt and constant self-evaluation—for an horizon of meaning and value. From this horizon inclusive of the good for the person as such that we then assign finality to the instru-

mental reason of scientific thought and technical praxis. At least as a longing that confers direction reason is open to a transcendence toward the good truth of the moral life.

In attention to the casuistic concern with the concrete experience of human life, we recognize the creature and imaginative function of the person in the implementation of principles while responsive to the personal as well as communitary history. Attention must also be given to pluralism and democratic dispositions. Only dialogue and persuasion in consonance with respect to individual autonomy promises to foster beneficence in terms of common goals, and of the formative of one's moral personality simultaneously with the formation of a culture in search of the good.

It is our expectation that a dialectic of reason and experience—perhaps in the tradition represented by natural law theory but centered on contemporary analysis of person in relation offer a philosophical framework for the physician-patient encounter. It supports a community of trust and inter-subjective fidelity in conscious contrast to adversarial, commercial, technical relation as model for genetic medicine. The extreme of paternalism—one rejecting consultation with the patient—as well as egocentric individualism can be evaded by way of the formation of a mutually reverential appreciation of the specific role of physician and patient in search of a common good of medicine. Essential to this reflection is a renewed sensitivity toward the uniqueness of the person-patient as well as professional clinician. Intuition and empathy serve to contact the living and often vulnerable and suffering patient, and also the compassionate and perhaps helpless health care professional. The ethical reflection here proposed is oriented to focus the physician-patient encounter as a relation of covenant exchange of trust in search of the good.

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