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Clarifying the Goals of Nondirective Genetic Counseling

In recent years, scientists have identified genetic mutations associated with a broad range of diseases, from rare conditions like Huntington's disease to certain forms of breast and colon cancer. These discoveries, in turn, have prompted the rapid development of genetic testing. Two different kinds of genetic tests are now in use. *Somatic* tests aim to detect a current disease or to identify disease susceptibilities in the patient being tested. *Reproductive* genetic tests detect mutations in germ cells and fetuses — mutations that are associated with disease in the patient's (potential) offspring.

The proliferation of genetic tests, and their significance for individuals beyond the patient tested, have increased the importance of genetic counseling — the effort to advise patients about the availability of genetic tests; to help them make informed and voluntary decisions about whether or not to undergo testing; and, if they choose to be tested, to enable them to understand and respond appropriately to genetic test results and diagnoses.

Despite occasional dissents, the standard view of genetic counseling is that it must be "nondirective." In using that term, many commentators emphasize two concerns: patient autonomy and value neutrality. They assume that these concerns are closely related, and that any expression of a counselor's values — or indeed, any moral discussion at all — undermines the ability of patients to make decisions for themselves.

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We may wonder, however, why genetic counseling should require any greater circumspection about values than is practiced in other areas of health care. One purpose of this paper is to argue that it does not. Properly understood, nondirectiveness requires the counselor to adopt whatever method best ensures that the patient's choices about genetic testing are informed and voluntary; it is centrally concerned with patient autonomy. But respect for autonomy is distinct from, and does not require, value neutrality. Indeed, the standard insistence on value neutrality may only make the goals of nondirectiveness more difficult to achieve.

Two Histories

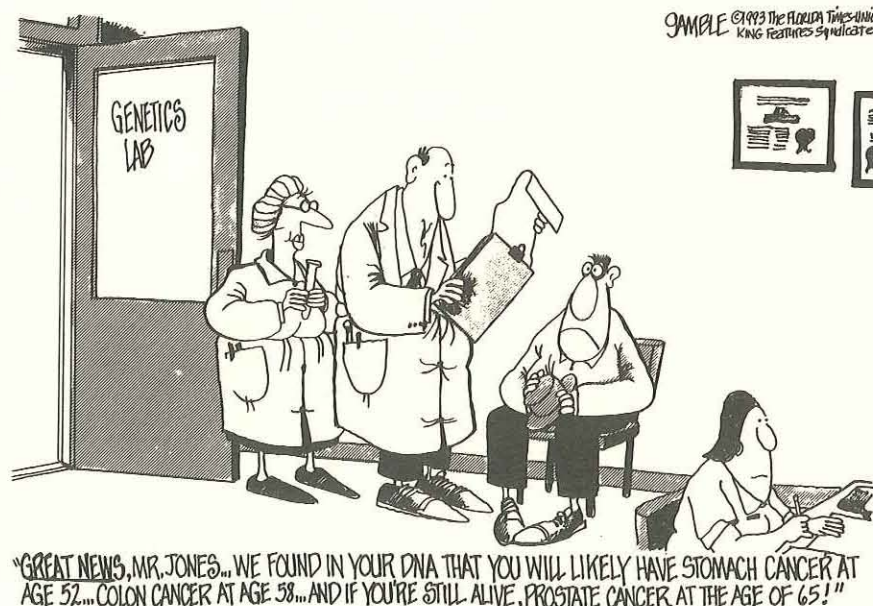
In order to understand why patient autonomy is central to nondirective genetic counseling, we must return to the generally agreed-upon aim of such counseling: enabling patients to understand and respond appropriately to genetic test results and diagnoses. The phrase "respond appropriately" is crucial, for it generates the main disagreements about the proper role of the genetic counselor. The nondirective approach insists that an appropriate response is one made by the patient herself. Whatever she decides is "appropriate," so long as her decision results from an understanding of the facts and truly reflects her values. Whether or not the counselor agrees with this decision is irrelevant.

This understanding of what constitutes an "appropriate response" to genetic diagnoses is still

relatively new. Early in this century, it was widely believed that an "appropriate response" was one that tended to promote genetic health and to eliminate genetic disease. Choices at odds with these purposes reflected ignorance, selfishness, or worse. Such notions of appropriateness were driven in large measure by the assimilation of genetic health to public health. Combating genetic disease was seen as a public health problem; someone who did not strive to promote genetic health risked not only her own well-being but also that of the "race." This approach quickly led to notorious abuses, from the practice of forced sterilization in the United States to the comprehensive eugenic programs in Nazi Germany. Policies intended to promote "genetic hygiene" did so at the expense of individual liberties and, often, lives.

Nondirective genetic counseling is a reaction to this history of abuse. It rejects genetic hygiene as its primary objective, and distances itself from abuses committed in the name of eugenics by attempting to ensure that patients' choices about testing and intervention are both informed and fully voluntary. Its goal is to make the patient aware not only of genetic risks, but also of her freedom to decide whether or not to be tested and how to respond to positive results.

More generally, the history of eugenics helps explain why we have genetic counseling at all. There is no special counseling profession associated with other medical tests: we do not have cardiac counselors or oncology counselors. But then, cardiac and oncology testing have no comparable history of being used against the patient's will and interests.



Ed Gamble

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The contemporary concern with value neutrality reflects a different history. A controversy over the relation between science and values, culminating at the end of the nineteenth century, took the form of a debate over whether the various social sciences were free of value claims and whether, if they were to make statements of value, they could still be truly regarded as sciences. By the early part of this century, the standard view was that scientific results neither confirmed nor refuted value claims. Thus, to assert such claims was to venture beyond the authority of science. Even now, scientists writing about values tend to treat them as merely psychological or social phenomena; they often use the terms "values" and "biases" interchangeably. In genetic counseling, a commitment to value neutrality is meant to secure the objective and scientific character of the counselor's communications.

Rightly understood, respecting autonomy and maintaining value neutrality are distinct concerns. Respect for autonomy means helping to ensure that the patient's choices regarding genetic diagnoses are informed and voluntary, reflecting her own values and interests. Thus, it serves the primary goal of nondirective genetic counseling. In contrast, maintaining value neutrality means expressing no opinion about the value of the medical procedures the patient faces, nor about the ethical issues the patient should consider in making her choice. Thus, value neutrality is best understood as a constraint on the counselor's interaction with the patient. The question is whether this sort of constraint is necessary, or even helpful, for the purpose of respecting autonomy. Why should genetic counselors be more constrained in their expression and discussion of values than other health professionals are?

Defending Value Neutrality

One answer to this question holds that in the specific context of genetic counseling, value neutrality is a necessary means of preserving patient autonomy. There are several arguments for this claim: (1) the genetic counselor's value judgments would enjoy a spurious scientific authority; (2) the expression of such judgments would lead counselors down a slippery slope to more coercive measures; (3) the autonomy of patients considering genetic testing is especially fragile; and (4) the social pressure on these patients is especially great. None of these reasons, however, can withstand scrutiny.

With respect to the first concern, nothing compels a counselor to present moral issues as matters of scientific judgment or give the impression that the values she expresses have the authority of science. So long as she carefully disclaims any special expertise in

matters of value, her expression of values may be compatible with a respect for the patient's autonomy.

Arguments to the contrary have often focused on the issue of what a counselor should say to a patient who asks, "What would *you* do?" Seymour Kessler argues that a forthright answer to such a question is inherently directive, since the "counselor attempts to create the illusion that he/she has taken responsibility for the counselees' actions and decisions." Certainly the counselor violates value neutrality in giving a direct response, in that she expresses her own values. If, however, the counselor also makes it clear that she has no greater expertise in making moral judgments than the patient, surely she will not appear to be taking responsibility for the patient's "actions and decisions." Indeed, she might well emphasize the patient's responsibility for a difficult choice, even as she explains how her values would inform her own decision.

Similarly, a counselor may violate value neutrality if she emphasizes the harms or costs of a particular reproductive decision, for example, the decision to give birth to a child whom genetic testing reveals to have a severe chromosomal disorder. But although the counselor's emphasis on the emotional and moral costs of creating a severely disabled child may reveal her own values, it may also enhance the decision-making process of a patient who has ignored or glossed over those costs — even, or especially, if she ultimately decides to have the child.

The second concern suggests that even if the expression of values is not objectionable in itself, it may be the first step in a process that would lead counselors, or the counseling profession, to adopt blatantly coercive measures. This may be a plausible concern if we assume that counselors would have difficulty expressing or advocating their own views without pressuring the counselee to adopt them. If, however, the counselor is committed to the goal of protecting the patient's autonomy, she will express her own values only to the extent that doing so serves that goal.

The third concern stems from a belief that patient autonomy in the context of genetic counseling is particularly fragile. The patient in a genetic counseling session is apprehensive, anxious, and unsure. She faces the possibility of receiving devastatingly bad news, or good news alloyed with guilt about being spared a fate that others suffer, often others very close to her. If the genetic counselor expresses a value judgment, the patient will acquiesce, since in this situation she has neither the strength nor the self-confidence to disagree. The patient's autonomy is so fragile that *any* influence undermines it. Thus, value neutrality must be maintained in order to respect the patient's autonomy.

Yet in other areas of medical practice, respect for autonomy is not thought to require extreme circumspection in the expression of values. No one has suggested that physicians, for example, should be barred from giving advice. Indeed, it is a common part of medical practice to offer patients advice, recommendations, warnings, and encouragement. None of these activities, if performed properly, is thought to threaten the patient's autonomy. Doctors are obliged to make sure that the patient is fully informed about her situation. They must acknowledge the need for her consent before initiating certain procedures, and they must support her rational assessment of the diagnosis. But as long as they fulfill these obligations, there is no objection to their expressing values or offering advice.

One may argue that a patient considering genetic testing faces great anxiety and conflict, and thus may be unusually impressionable. But the same might be said of a desperately ill patient deciding whether to undergo risky but potentially life-prolonging surgery or chemotherapy. A cardiac or oncological surgeon who responds candidly to a patient's anxious inquiry about what she would do in his place may reveal strong values about health and risk. But we would not regard her candor as threatening the patient's autonomy. It may be that the authority and prestige of doctors in general is so great, and their patients so dependent and vulnerable, that all doctors should forswear advice and argument. But that would radically, and detrimentally, restrict the doctor-patient relationship, turning the personal physician into an impersonal medical technocrat.

The fourth reason for thinking that respect for autonomy requires value neutrality focuses on the social pressure that, it is argued, is peculiarly associated with reproductive testing — social pressure to test for, and abort, "defective" fetuses. A patient who contemplates genetic testing may confront an oppressive social consensus that a patient considering cardiac or oncological testing does not face.

We need not assume, however, that genetic counselors who engage in moral dialogue with their patients will become mere enforcers of social pressures. In fact, they might succeed in making those pressures less insidious. By articulating the reasons and values that underlie a social consensus, and by providing a noncoercive setting where patients can assess these reasons and values, they may help the patients see their options as agreement or disagreement, rather than acquiescence or defiance.

Is Value Neutrality Possible?

Beyond these refutations of common arguments, there is another reason for separating respect for

autonomy from value neutrality: in the context of genetic counseling, value neutrality may not be possible. In the first place, autonomy is itself a value about which the counselor cannot be neutral. Second, promoting awareness of genetic testing, especially reproductive testing, seems fundamentally incompatible with value neutrality.

As we have seen, the standard view defines autonomy as the primary value in nondirective genetic counseling. Counselors and patients, however, often differ as to the importance of autonomy. Patients do not always regard reproductive decisions as theirs to make; they may often defer uncritically to the judgments of their spouses, family, or religious leaders. Thus, the essential principle of nondirectiveness — that the patient is to be treated as the decision-maker — departs from neutrality with regard to a very controversial issue.

One might argue that the genetic counselor should remain neutral about all values *except* the paramount value of patient autonomy. But this is not possible, either. The very development and promotion of reproductive genetic testing conveys the impression that something should be done when an abnormal genetic condition is detected. The implicit assumption is that the condition should be eliminated — which, given the limitations of present technology, almost always means terminating the pregnancy. The genetic counselor may not share this view; but as the person who mediates the patients' encounter with the technology, she cannot stand apart from it. As Angus Clarke argues:

I contend that an offer of prenatal diagnosis implies a recommendation to accept that offer, which in turn entails a tacit recommendation to terminate a pregnancy if it is found to show any abnormality. I believe that this sequence is present irrespective of the counselor's wishes, thoughts, or feelings, because it arises from the social context rather than from the personalities involved — although naturally the counselor may reinforce these factors.

We may recognize the force of these concerns if we imagine an expensive and risky prenatal test for eye color or hair color. Most of us would probably insist that a genetic counselor should not even offer her patients such a test, since eye or hair color should have no relevance to the patient's reproductive choices. To invite the patient to consider a test with more than minimal costs and risks is, at the very least, to suggest that the test has such relevance. This is a significant departure from value neutrality, and the values it implicitly endorses are eugenic in nature. The genetic counselor can help to ensure that the patient makes her own decision about whether to accept those values and undergo testing, but she cannot proclaim her complete neutrality with respect to them.

There are, finally, more general reasons for doubting that value neutrality is possible. One important function of the counselor is to provide information on risk, but the communication of risk cannot be neutral. For example, the counselor must choose between characterizing a risk as a probability of a loss or a probability of a gain. That choice is no more neutral than the choice between describing a glass as half-empty or as half-full. Such "framing" involves a departure from value neutrality, and there is strong evidence that it influences the patient's decision. As one researcher found in a study of outcome framing and patient decisions, "surgery appeared to be much more attractive when the options were framed in terms of the probability of survival rather than in terms of the probability of death."

The fact that value neutrality is difficult or impossible in the context of genetic counseling does not mean, of course, that the counselor should give free reign to her values, treating the counseling session as an opportunity to mount a "bully pulpit." The purpose of counseling is to help the patient make her own decision, not to persuade her to decide a particular way. In some cases, the counselor will enhance the patient's autonomy by being forthcoming about her own values, convictions, and experiences. But this will not always be the case. A counselor who preached to her patients would almost certainly do a poor job of enhancing their capacity for independent decision-making. But what should constrain the counselor's expression of value is a concern for the patient's autonomy, not the illusory ideal of value neutrality.

The Challenge of Genetic Counseling

In their efforts to respect patient autonomy, genetic counselors must address two distinct sets of issues: (1) empirical issues about the effect of tacit and expressed values on the patient's capacity to make a knowing and fully voluntary choice; and (2) conceptual issues about the meaning of autonomy in the context of genetic testing.

One empirical issue is whether the social pressures accompanying the screening, testing, and counseling processes are more likely to threaten autonomy when they are made explicit or when they are permitted to operate *sub rosa*. There is reason to suspect that the latter is more subversive of autonomy than the former. Social psychological research suggests that social pressures affect behavior most strongly when they are unspoken. In contrast, explicit efforts to control behavior often backfire, provoking autonomy-preserving resistance. Other empirical research suggests that overtly directive counseling is not terribly coercive in its effect. Professor Kessler cites

studies from communist-ruled Eastern Europe, including one in Hungary which found that "even under social and political conditions where directiveness is expected, nearly 40 percent of counselees with high genetic risks did not take the counselor's advice."

A second empirical issue has to do with the effects of giving patients a very concrete appreciation of the options available to them. For example, what if genetic counselors established contact between prospective parents who receive positive results on a prenatal test and the parents of children who have the condition that has been tested for? Exposure to parents who decided not to terminate a pregnancy, and who did not regret their decision, may act as a powerful corrective to the social pressure to terminate.

The conceptual issues are more complex. Many of the major debates in medical ethics involve questions about what autonomy means in particular contexts, what external factors threaten or subvert it, and what weight it should have in conflicts with other values. Do we respect a person's autonomy by enforcing her living will or by yielding to her semi-comatose resistance to the termination of life support? Do we enhance or threaten autonomy by giving a patient information about the risks involved in a surgical procedure, when she has not indicated a desire to learn those risks or has even indicated a desire not to know them?

The most familiar controversy over patient autonomy in the context of genetic testing concerns sex selection: should the geneticist assist a patient in finding out whether her fetus is of the "wrong" sex, or is the commitment to her autonomy outweighed by our objections to her decision criteria? Dorothy Wertz and her colleagues have documented a shift among health professionals, from refusal of assistance to compliance with the patient's desires, as patient autonomy has become more firmly entrenched as a dominant value in health care. Although fetal sex selection involves a sharp moral conflict, the rejection of value neutrality offers the geneticist an option besides outright refusal and silent acquiescence; she can explore and challenge the reasons for her patient's sex selection preferences, even if she ultimately accepts the patient's decision.

Counselors must also consider whether they better respect autonomy by providing the patient with more information, or by letting the patient decide how much information to receive. On a view that associates autonomy with rationality, a patient's autonomy can only be enhanced by the receipt of accurate information; on a view that emphasizes the patient's control over the decision-making process, the communication of unsought information may violate autonomy. Even the attempt to tell the patient that she

may choose whether to receive or decline certain information is filled with difficulties. If the counselor describes these options, he unavoidably imparts some information the patient may not want to receive. On the other hand, if a counselor mentions information only when the patient requests it, he risks keeping the patient in ignorance of facts she would very much like to have but does not know enough to ask for.

Finally, difficult issues arise when patients accept, or acquiesce in, the judgments of others with respect to their reproductive decisions, or when they actively delegate control over these decisions to spouses, parents, in-laws, or religious leaders. The counselor must decide whether she respects her patient's autonomy more by deferring to the patient's willingness to let others make her decision or by insisting that the patient regard the decision as her own. Does she let the patient decide who will take part in the counseling session; does she intervene in the ensuing conversation to make sure that the patient expresses her own views? Should the counselor distinguish between patients who voluntarily delegate decision-making authority to others in order to escape responsibility, reduce anxiety, or circumvent weakness of will, and those who fail even to recognize that the decision is theirs to delegate?

The ideal of nondirective counseling takes us only so far in addressing such critical questions. What is needed is careful discussion about the meaning and relative weight of autonomy and other values central to counseling and health care. The demand for value neutrality only confuses the issues and poses obstacles to their resolution.

— Robert Wachbroit and David Wasserman

This article is adapted from an essay appearing in the *Stanford Law & Policy Review*, vol. 6, no. 2 (1995). Sources: Lori B. Andrews, et al., eds., *Assessing Genetic Risks: Implications for Health and Social Policy* (National Academy Press, 1994); Seymour Kessler, "Psychological Aspects of Genetic Counseling. VII. Thoughts on Directiveness," *Journal of Genetic Counseling*, vol. 1, no. 1 (1992); Angus Clarke, "Is Non-Directive Genetic Counselling Possible?" *Lancet*, vol. 338 (October 19, 1991); Dorothy C. Wertz, John C. Fletcher, and John J. Mulvihill, "Medical Geneticists Confront Ethical Dilemmas: Cross-cultural Comparisons among 18 Nations," *American Journal of Human Genetics*, vol. 46 (1990).

Public Lands in the Next Century

In remarks he made before the U.S. Senate in 1832, Henry Clay observed that "no subject which had presented itself to the present, or perhaps any preceding Congress, was of greater magnitude than that of the public lands." For most of our nation's history, his words would not have seemed an exaggeration. The acquisition of the Louisiana Territory, the railroad land grants, and the Homestead Act mark well-remembered stages in the development of the United States in the nineteenth century. At the opening of the twentieth century, the adoption of a dam-building and irrigation program and the creation of the U.S. Forest Service were leading elements in the Progressive agenda of Theodore Roosevelt. Over the past quarter-century, the designation of wilderness areas, the preservation of federal forest lands in the

Pacific Northwest to protect the habitat of the spotted owl, and the setting aside of public lands in new national parks and wildlife refuges in Alaska have been defining achievements of the environmental movement.

The public lands are engraved in our collective imagination; they have played a crucial part in shaping American culture. Yet this rich symbolism has not yielded corresponding benefits for the land. Despite the noble intentions of policymakers and legislators, the governance of the public lands over the past two centuries has seldom achieved its most ambitious goals.

The Homestead Act of 1862, for example, provided that each settler could acquire 160 acres of free public land by residing on and cultivating this land for five