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The Personal is Political, the Professional is Not:

Conscientious Objection to Obtaining/Providing/Acting On Genetic Information

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Abstract

Conscientious objection (CO) to genetic testing raises serious questions about what it means to be a health care professional (HCP). Most of the discussion about CO has focused on the logic of moral arguments for and against aspects of CO and has ignored the social context in which CO occurs. Invoking CO to deny services to patients violates both the professional's duty to respect the patient's autonomy and also the community standards that determine legitimate treatment options. The HCP exercising the right of CO may make it impossible for the patient to exercise constitutionally guaranteed rights to self-determination around reproduction. This creates a decision-making imbalance between the HCP and the patient that amounts to an abuse of professional power. To prevent such abuses, professionals who wish to refrain from participating have an obligation to warn prospective patients of their objections prior to establishing a professional-patient relationship or, if a relationship already exists, to arrange for alternative care expeditiously.

Keywords

conscientious objection; genetic testing

INTRODUCTION

Medical Conscientious Objection in Context

Conscientious Objection (CO) to participation in medical interventions is not a new phenomenon among health professionals. Allopathic physicians, in the mid-nineteenth century, used the Hippocratic prohibition against performing abortions to claim a superior moral stance over other practitioners of the healing arts and to drive the competitors from a crowded medical marketplace. The struggle for market control was framed in terms of ethics, rather than evidence that allopathic therapeutics produced superior outcomes [Mohr, 1978]. Whoever the desperate patient consulted, whether an Allopath, Osteopath, Naturopath, Hydropath, or Thompsonian, that practitioner of the healing arts was able to provide treatment options with only a modest probability of success. More than a little truth supported the observation, attributed to the senior Oliver Wendell Holmes, that "if all of the medical armamentarium of the day were to be thrown into the ocean, so much worse for the fish, so much better for the people."

The establishment of allopathy as state-sponsored medical orthodoxy, as well as the marginalization and stigmatization of alternative systems, succeeded, in part, because of an intense public moral crusade against abortion. The campaign helped establish the American Medical Association as the semi-official voice of the medical profession. Further, the social ties allopathic physicians had through class background, education, and religious affiliation with other established political and commercial elites served to solidify their dominance. One indicator of the convergence of the values of allopathic physicians with other elites was the number of medical school commencement addresses delivered in the nineteenth century by pastoral leaders emphasizing the work of physicians as a sacred calling [Imber, 2008].

As the twentieth century progressed, the association of medical work with a religion eroded; the laboratory bench replaced the church pew as the symbolic locus of legitimacy and authority for health care professionals. In the early years of the twentieth century, the Flexner Report established a template for U.S. medical education. In the second half of that century, the federal government expanded its role in the financing of biomedical research and made possible the growth of the research university. With dramatic clinical advances such as vaccines for childhood diseases, effective antibiotic therapies, safe and efficient transfusion of blood products, and organ transplantation the science of medicine waxed as its art waned. Sinclair Lewis' *Arrowsmith* documents this transformation of the physician from a person of uncertain skills and sketchy knowledge to a person of science and a heroic figure methodically struggling against the unknown to better the human condition [Rosenberg, 1979].

By mid-century, sociological definitions of the medical profession emphasized the following characteristics: a long period of adult socialization in a body of specialized knowledge related to health, possession of a shared ethical code, autonomy and regulation of practice by peers, and a service ethic that placed the needs of patients above the interests of physicians [Parsons, 1951]. For most of the remainder of the century, sociological discussion of the profession focused on whether such definitions confused the self-serving rhetoric that the medical profession used to establish, preserve, and reap the economic benefits of monopolistic control for empirical reality [Freidson, 1970a, 1970b, 1993; Bosk, 2006]. The possession of a shared code of ethics was, no doubt, influential in formation of state policy regulating medical affairs. Understanding the deference the state showed to the medical profession in formulating policy requires understanding the nature of professional ethics and claims based on them. Such claims *did not* depend on personal systems of belief. Rather, professional codes of ethics were collective; socially shared; a communal possession formed and reinforced by passing through a set of common educational rites, rituals and ordeals; and avowedly secular to meet the demands of a religiously diverse, pluralistic society.

Conscientious Objection and Medical Genetics in the 20th and 21st Centuries

Times change, but not that much. Once again, an identifiable group of health care professionals claim the right to deny services based on COs supported by moralistic arguments. However, a fundamental feature differentiates the COs that HCPs make today from those that were made their counterparts in mid-nineteenth century America. Contemporary claims rest upon individual idiosyncratic beliefs that have little to do with the shared belief system of the professional community; CO is now justified by beliefs one holds as a member of some communal group external to one's affiliation with the medical profession. Most commonly, COs to the provision of services are made in domains of practice that surround birth and death, which, not coincidentally, are those domains closest to religious values.

The health care professionals (HCPs) most likely to claim the privilege of CO include obstetricians, pediatricians, medical geneticists, and genetic counselors. HCPs exercise the

privileged claim of CO when they refuse to order tests for or provide information to patients/clients (hereinafter, “patients”) pertaining to one or more genetic diagnoses. In such cases, HCPs argue that their actions could lead patients to choose either pregnancy termination or the use of pre-implantation genetic techniques that involve discarding embryos. Because HCPs view embryos as rights-endowed persons, they object to any action that facilitates their destruction.

A proportion of COs not only refuse to inform patients about available prenatal genetic testing but also refuse to refer the patients to practitioners who have alternative views. Objectors often invoke their individual “right” to act as autonomous moral agents according to their deeply held religious or philosophical beliefs [Wicclair, 2000; Chervenak and McCullough, 2002; Curlin et al., 2007]. According to this view, freedom to practice one’s religion trumps one’s obligation as a professional to provide services to the patients who come to them. Essentially, HCPs who possess specialized skill or knowledge and who refuse to provide either services or referrals claim a moral veto over not just their patient’s judgment but that of the larger community as well. Engaging in the “extended” refusal (failure to discuss alternatives or refer to practitioners whose lack of moral sensitivity permits them to provide these services) rests on the notion that providing information constitutes complicity in immoral behavior. The HCPs who engage in the extended form of CO shift the responsibility or burden of discovering and acting on alternatives to the patient or surrogate.

Indeed, in discussing the results of their national survey of U.S. physicians identifying the frequency of CO and the characteristics of physicians who appeal to it in their practices, Curlin and colleagues [2007] assert that patients, not HCPs, have responsibility for ascertaining their physicians’ beliefs. They state “[Patients] should ask their doctors *ahead of time* whether they will discuss” [emphasis added] controversial “interventions for sexual and reproductive health and end-of-life care.” They conclude, “If a patient wants a treatment that the physician will not provide, the patient may choose to consult a different physician.”

How exactly the authors derive this particular normative ‘ought’ from the aggregated empirical ‘is’s’ of survey data is mysterious; it is one thing to report on the beliefs of respondents, and quite another to endorse them and, in so doing, shift responsibility to patients who are not necessarily in a position to know what is controversial and what is not. Rather than making it easier for patients to exercise their autonomy, the authors’ position makes it harder. One wonders how the conscientiously objecting HCP could discuss the patient’s desire for services that practitioners find objectionable in ways that do not evoke embarrassment or shame in the patient. Further, one person’s controversy is another person’s routine, especially when society deems the requested service legitimate. Many patients will discover that the requested procedure involves controversy only at the moment the HCP demurs.

For some HCPs, the rationale for CO rests on other fundamental moral principles besides the autonomy of professionals. In a letter to the editor responding to Curlin, et al, O’Connell and Mistrot [2007] assert that physicians have a responsibility to prevent patients from “harming themselves” and thus doctors cannot “help [patients] procure” objectionable interventions. Asch [2006], in a different venue, noted the importance of HCPs’ declaration of CO to requests from patients. She states that in order to preserve their moral agency, HCPs must act conscientiously, rather than slavishly follow patients’ dictates. These muscular assertions of an extensive refusal based on individual conscience assume that doctors retain a paternalistic obligation to block a patient’s ill-advised exercise of self-determination, even if the US Supreme Court has found that such self-determination is fundamental to any schema of ‘ordered liberty’ [Curlin et al 2005].

Professional Ethics and Personal Power

While we cannot here overcome the difficulty inherent in establishing the ascendancy of competing sets of moral values or other attempts to reconcile philosophical differences over CO, we cannot avoid taking notice of how the assertion of CO by HCPs reverses a half-century's efforts to extend patient choice and, in effect, acts to limit the flow of information necessary for such choice. How much this is the case becomes clear when we focus on two generally neglected aspects of the debate over CO: 1) the departure from the tradition of professionalism necessary for asserting that CO is a legitimate basis for action and 2) the related and disturbing failure of those asserting a extensive right to CO by HCPs to acknowledge the remarkable asymmetries in power, authority, social and economic status, knowledge, and skills, as well as access to the specific services, between most HCPs and their patients. CO only makes sense when one of two conditions applies: 1) all parties have more or less equal footing on the social and political playing field on which the objections are raised, debated, and settled or 2) the objecting parties have substantially less social capital than policy and/or rule makers and CO constitutes a form of protest against oppressive authority.

In the latter case, at least as it seems to have played out in the history of the United States, objectors clearly recognize their inferior position, engage in acts of civil disobedience based on their moral values and accept the legal and social consequences that results when they act on the basis of their conscience. When COs are civilly disobedient, they know and expect that they will go to jail or pay fines. In fact, the dramaturgical and polemical power of CO rests on drawing an otherwise uninvolved public's attention to unjust law or oppressive authority in order to create political change. Martin Luther King's letter from the Birmingham Jail derives its power not just from the eloquence of the argument it contains but also from the legal system that required him to write the letter in jail in the first place. It is hard to imagine that the same words titled 'Letter from the Birmingham Public Library' having the same impact.

In the current disputes over CO in health care, objectors depart from this traditional strategy for legal change—none in the recent literature have clearly indicated a willingness to settle for anything less than continued employment, professional status, and/or general social privilege. Today, those HCPs who assert the right to object on conscientious grounds to provision of prenatal diagnostic services have expressed no willingness to bear any burden or to pay any price to defend a freedom it is not at all clear they properly possess. HCPs endorsing an extensive CO fail to consider with appropriate seriousness how their claims to conscience are balanced against the competing claims of patients to exercise their conscience. In fact, HCPs' assertions of conscience display such an apodictic certainty and such disdain for the opposed conscientious claims of patients that any meaningful public discussion of CO, the conditions under which one ought rightfully exercise it, or the circumstances in which CO is reasonably limited are short-circuited. The contemporary statements that endorse an extensive right to CO have the sound of one hand clapping, wildly.

Discrepancies between professionals' values and those of patients requesting particular services are not unprecedented. The study of previous conflicts illustrates how the social and political context both inside and outside of the medical profession influences behavior. Nathanson and Becker [1981] considered the controversies over abortion in a series of papers in the 1970s and '80s. They addressed the relationship between the willingness of obstetricians to perform abortions and the social environment in which the physicians practiced. Based on a survey of private practitioners in Maryland, they concluded that those predisposed against providing legal abortions, by virtue of religion or conservative values, more readily refuse to perform the procedure or refer for it when practicing in a conservative

rural setting and participating in their local medical society. However, they also observed that “personally conservative obstetricians would provide abortion services *if* these services were supported by prevailing professional norms” [emphasis in original] in their primary hospitals or medical communities. Extending the logic of these findings to the present, a reasonable speculation is that the current wave of support for CO stems in part from a political climate where government leaders openly oppose abortion or end-of-life options such as the discontinuation of fluids and nutrition in patients in a permanent vegetative state. In a political environment less supportive of their beliefs, we might see fewer emboldened pleas from physicians to oppose patients’ requests for interventions based on the doctor’s personal beliefs.

In any case, the debate over CO has only indirectly addressed the social meanings of medical professionalism. Blustein and Fleischman [1995] place the dilemma of the “pro-life” maternal-fetal medicine in the realm of “physician integrity.” However, defining the issue this way only moves the discussion to a different level of abstraction. Moreover, reframing the problem as one of “physician integrity” provides little guidance in determining how to balance personal beliefs and professional values to achieve or preserve this integrity. Classically, society gives medical professionals the right to use their specialized knowledge and judgment on behalf of and in consultation with their patients (and/or appropriate surrogates), in exchange for considerable freedom to set the conditions of their practice. The social contract between medical professionals and the lay public provides medical professionals substantial economic reward and social status. These benefits are not merely a reward for the personal sacrifice required during the arduous and prolonged adult socialization that physicians’ work requires but is also an attempt to mitigate any temptation to exploit the patient’s vulnerability for profit.

In large measure, the responsible exercise of professional knowledge, skill and judgment requires that medical professionals recognize that few patients have the background or capacity to assess accurately their physician’s recommendations. The patients’ lack of competence, their helplessness and their inability to act on their own to remedy their health problems makes necessary a physician’s obligation as a fiduciary. The definition of fiduciary responsibility entails a physician’s willingness to put patients’ interests ahead of personal profit as well a willingness to make personal sacrifices and assume some personal risk. A long and proud tradition exists of physicians’ brave actions in the face of plague, influenza and tuberculosis outbreaks and on the battlefield. Indeed, part of the social crisis surrounding the emergence of AIDS in the U.S. in the 1980s and 1990s involved the breakdown of HCPs’ willingness to assume risk, in contrast to other critical infectious disease crises, based on the social characteristics of HIV-infected population [Bosk and Frader, 1988].

Whose Responsibility?

Placing the patient before self surely makes up one of the hallmarks of professional, including medical, ethics. What value, personal integrity or eschewing personal interests, trumps the other? As Blustein and Fleischman [1995] note, “What integrity demands of [the maternal-fetal medicine specialist] is not single-minded and inflexible adherence to his personal pro-life principles, but rather the recognition that he is committed to multiple and sometimes conflicting values....” In our view, being a conscientious medical professional may well mean at times acting in ways contrary to one’s personal ideals in order to adhere to a general professional obligation to serve patients’ interests first. Widespread failure of health care professionals to take the moral injunction to put patients first would have grave implications for trust in physicians and other HCPs, if not for the very maintenance of social order.

Having argued that professionalism's meaning in the social world is determined by how HCPs honor patients' needs and values when they diverge from the provider's, we also need to address the problem of the social asymmetry of knowledge and power that typifies the relationship between HCPs and patients. Simply put, where society permits patients to obtain medical services and where no clear-cut moral consensus opposes those services, physicians who invoke CO to providing those services risk abusive exercise of their state-licensed power and authority. To the extent that the HCP's position of power and privilege rests on an education that is, in part, subsidized by the state, withholding socially permitted interventions is problematic. As Wicclair [2000] has argued, "if physicians who have conscience-based objections were given blanket permission to refuse to directly or indirectly help patients achieve their goals, there is a risk that patients...would not have an effective right to..." achieve socially legitimized care.

Assuming that it is undesirable to coerce HCPs to perform procedures that they find morally objectionable, one has to address the problem of social control over the physician's right to refuse to provide services that their peers accept as unproblematic. Curlin et al [2007] imply that physicians need only refuse to intervene and are permitted to do what is necessary to avoid complicity with an act the particular physician considers morally unacceptable. In other words, the obstetrician is allowed simply to ignore the request of a pregnant woman seeking amniocentesis to see if her fetus has a genetic disorder and not to discuss with her the risks that the fetus has the condition. There is no fiduciary obligation either to counsel her regarding the benefits and risks of the sought-after procedure or to assist the woman in finding another physician willing to perform the procedure. Moreover, the burdens of finding a more appropriate physician in a timely way so that a pregnancy termination might occur with maximum safety falls to the woman, the party who is both most emotionally burdened and has least access to necessary information.

Surely professional ethics, if not simple human decency, requires HCPs objecting to such use of genetic information to inform potential patients prior to those patients having to incur the costs, inconvenience, and insult of entering into a relationship that the physician knows ahead of time cannot be consummated. As Wicclair [2000] states, physicians who anticipate a CO to patients' requests should "clearly inform patients *in advance* of any value commitments that will restrict the range of services that the physician is willing to provide" (emphasis in original). Only letting patients know about such restrictions up front ensures fairness to patients and prevents HCPs from abusing their professional power. In the few circumstances where a relationship exists between patient and HCP, who now wishes to invoke CO, considerations of both equity and respect require the HCP to refer the patient. When HCPs engage in extensive CO and fail to provide their patients an alternative, they risk leaving the patient "worse off," a situation that appears to violate the Hippocratic injunction 'to do no harm.' [Davis, 2004].

One peculiar feature of the whole debate about the HCP's right to invoke CO to deny services or, in its more expansive form, information about available services to patients is the shifting of the burden for finding care to the less powerful patient who has been denied a legitimate claim for service. Both decency and efficiency favor the opposite solution, placing the burden on the HCP, who has access to the resources required for making the appropriate referral. In addition, a second puzzle exists with regard to HCPs use of CO. Specialty choice in the American health care system is a matter of individual choice for the doctor-to-be. Why would individuals choose a specialty in which the provision of routine service involves so many procedures that they find morally objectionable on personal grounds? Why have the associations of professional specialties not taken a more forceful stand to protect patients' rights to legitimate services?

Conclusion

We have argued that CO to genetic testing raises serious questions about what it means to be a HCP. Most of the discussion about CO has focused on the logic of moral arguments for and against aspects of CO and has ignored the social context in which CO occurs. In many cases, invoking CO to deny patients services they request violates the professional duty to respect the patient's autonomy. Further, the HCP exercising the right of CO in this context may make it impossible for the patient to exercise self-determination around reproduction. The imbalance between a service denied because of a personal objection by the HCP and the denial of access to care necessary for the exercise of individual liberty that is constitutionally guaranteed is at best an abuse of professional power. To prevent such abuses, professionals who wish to refrain from participating have, at the least, an obligation to warn prospective patients of their objections prior to establishing a professional-patient relationship or, if a relationship already exists, to arrange for alternative care expeditiously [Ross and Clayton, 2007] .

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Charles Bosk is a medical sociologist who has researched, using ethnographic and other qualitative methods, surgical residency, genetic counseling services in a pediatric hospital, decision-making processes in a pediatric intensive care unit and the emergence of clinical bioethics. His major research interest continues to be the social definition and management of medical error and the process of graduate medical education. His work on error is supported Health Investigator Award from The Robert Wood Johnson Foundation

REFERENCES

- Adams K, Cain JM. The genetic revolution: new ethical issues for obstetrics and gynaecology. *Best Pract Res Clin Obstet Gynaecol.* 2002; 16:745–756. [PubMed: 12475552]
- Asch A. Two cheers for conscience exceptions. *Hastings Cent Rep.* 2006; 36:11–12. [PubMed: 17278865]
- Beckwith FJ, Peppin JF. Physician value neutrality: a critique. *J Law, Med Ethics.* 2000; 28:67–77. [PubMed: 11067635]
- Bluestein J, Fleischman AR. The pro-life maternal-fetal medicine physician: a problem of integrity. *Hastings Cent Rep.* 1995; 25:22–26.
- Bosk C. Review Essay: Avoiding Conventional Understandings: The Enduring Legacy of Eliot Freidson. *Sociology of Health and Illness.* 2006; 28:637–653. [PubMed: 16910950]
- Bosk C, Frader J. AIDS and Its Impact on Medical Work: The Culture and Politics of the shopfloor. *Milbank Q.* 1990; 68(Suppl. 2):257–279. [PubMed: 2381385]
- Chervenak FA, McCullough L. A group practice disagrees about offering contraception. *Am Fam Physician.* 2002; 65:1230–1232. [PubMed: 11925099]
- Curlin FA, Lantos JD, Roach CJ, Sellergren SA, Chin MH. Religious characteristics of U.S. physicians: a national survey. *J Gen Intern Med.* 2005; 20:629–634. [PubMed: 16050858]

- Curlin FA, Lawrence RE, Chin MH, Lantos JD. Religion, conscience, and controversial clinical practices. *N Engl J Med*. 2007; 356:593–600. [PubMed: 17287479]
- Davis JK. Conscientious refusal and a doctor's right to quit. *J Med Philos*. 2004; 29:75–91. [PubMed: 15449814]
- Freidson, E. *Professionalism: The Third Logic*. University of Chicago Press; Chicago: 2001.
- Freidson, E. *Profession of Medicine*. Harper and Row; New York, NY: 1970a.
- Freidson, E. *Professional Dominance*. Aldine-Atherton; Chicago, IL: 1970b.
- Imber, J. *Trusting Doctors: The Decline of Moral Authority in American Medicine*. Princeton University Press; Princeton, NJ: 2008.
- Lantos JD, Curlin FA. Religion, conscience, and clinical decisions. *Acta Paediatr*. 2008; 97:265–266. [PubMed: 18298771]
- Mohr, J. *Abortion in America: The Origins and Evolution of National Policy, 1800-1900*. Oxford University Press; New York: 1978.
- Nathanson CA, Becker MH. Professional norms, personal attitudes, and medical practice: the case of abortion. *J Health Soc Behav*. 1981; 22:198–211. [PubMed: 7288128]
- O'Connell P, Mistrot J. Letter to the editor. *N Engl J Med*. 2007; 356:1891.
- Parsons, T. Social structure and dynamic process: the case of modern medical practice, in *The Social System*. The Free Press; New York, NY: 1951.
- Rosenberg, C. *No Other Gods: Science and Social Thought*. Johns Hopkins University Press; Baltimore, MD: 1976.
- Ross LF, Clayton E. Letter to the editor. *N Engl J Med*. 2007; 356(18):1890.
- Wicclair MR. CO in medicine. *Bioethics*. 2000; 14:205–227. [PubMed: 11658133]