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The Duty to Recontact: Benefit and Harm

To The Editor:

The survey by Fitzpatrick et al. (1999), "The Duty to Recontact: Attitudes of Genetics Services Providers," represents a significant contribution to, and an important step forward in, the resolution of a complex and troubling issue. But, in both their Introduction and their Discussion, the authors refer to statements of mine (Sharpe 1994*b*) that have been taken out of context and therefore misrepresent my position on this issue. More critically, Fitzpatrick et al. have failed to take note of medical principles and legal obligations that are fundamental to discussion about whether a duty to recontact exists within the context of medical genetics and genetic counseling.

For example, the authors wrote that I stated "a physician's duty of care toward patients is considered to include the obligation to advise them of any developments in management and treatment that would be beneficial or detrimental" (Sharpe 1994*b*). This statement, in the context in which it is presented, is incorrect. My article (Sharpe 1994*b*) focused on the psychological aspects of presymptomatic testing for Huntington disease and, in particular, on whether a geneticist would have a continuing obligation to provide psychological support after disclosure of the test results. This issue was examined within the context of a physician's traditional postoperative duties of care to a patient, including the duties to monitor a patient's condition, to provide appropriate aftercare, to refer, and not to abandon the patient. As cited in my article, such obligations have long been recognized in the various codes and principles of ethics of organizations such as the American Medical Association and the Canadian Medical Association.

With respect to Huntington disease, because of the potential for and the nature of the psychological and psychiatric responses associated with risk clarification or a clinical diagnosis, I suggested that, in the same manner in which a physician may have a duty to continue treatment until recovery is complete, a geneticist may have a continuing duty of care until appropriate psychological or psychiatric counseling has been arranged. Once such counseling has been secured, however, the geneticist's obligation would come to an end.

In the same article, with respect to phenylketonuria, I also speculated—as evidenced by my explicit use of the term "theoretically"—that, because of the necessity of maintaining a low-phenylalanine diet and the fact that the gene technically has been expressed, a geneticist might have a duty to monitor a patient's condition over

a prolonged period of time (assuming that an appropriate referral could not be arranged).

Both of these clinical scenarios concern situations in which the patient may require *immediate* and continuing treatment and management. Strictly within this context, I wrote, "This duty to monitor may include the obligation to advise of any developments in management and treatment that would prove of benefit or detriment to the patient" (Sharpe 1994*b*). At no time did I suggest that either of these scenarios were examples of, or would support the concept of, a duty to recontact *former* patients. Indeed, the duty to recontact was never mentioned in my article.

With respect to a physician's continuing duty of care, as cited (Sharpe 1994*b*), American and Canadian courts of law have created a number of *distinct* categories in which to interpret a physician's duty to monitor, to refer, not to abandon, and to provide appropriate care. Generally speaking, these categories include: (1) advising a patient of the nature of her or his medical status; (2) providing a proper follow-up, which may include an obligation to instruct a patient about all appropriate precautions that must be carried out subsequent to treatment and/or an obligation to carry out regular medical examinations to monitor the patient's medical condition; and (3) a continuing duty of care, recognized by a number of American jurisdictions, when a risk of future injury arises from the original patient-physician relationship (Tresemer v. Barke 1978).

What these categories have in common, however, is the fundamental medical issue—not cited by Fitzpatrick et al.—of whether a patient is in continued need of a physician's *expert care* (Sharpe 1994*b*). In the past, the term "expert care" has been resolved within the traditional context of treatment and cure. In phenylketonuria and Huntington disease, because a patient may require immediate treatment and management, the geneticist or physician arguably will have a continuing obligation to provide such expert care until an appropriate referral has been arranged.

These particular examples, however, do not a general rule make. And they are substantially different from the concept, incorrectly attributed to me (among others) by Fitzpatrick et al. (1999), that a geneticist or physician may have a continuing obligation "to recontact former patients about advances in research."

The duty to recontact described by Fitzpatrick et al. is not necessarily concerned with the existing medical and legal issues of whether *continuing* expert treatment is required. Rather, this duty represents a *new* "ethical" or "moral" obligation (Fitzpatrick et al. 1999) to contact patients, years after an original test was completed, in order to inform them that a new or more accurate diagnostic or risk-clarification genetic test is available.

Medical genetics and genetic counseling represent a therapeutic model of care analogous to, but distinct from, the practice of medicine. For many genetic diseases, treatment and cure are not available. Predictive genetic testing, for example, is concerned primarily with providing information about a medical condition that is likely to occur at some time in the future. Because of such limitations, the medical genetics and genetic-counseling communities have recognized that if physicians are to provide benefit and to prevent harm to the patient before, during, and after genetic testing, physicians will have to develop a more "human vision" of care, focusing on the patient's informational, communicative, emotional, and psychological needs (National Society of Genetic Counselors 1997), as opposed to a purely "medical vision" restricted to the treatment and cure of physical disease.

It must be acknowledged that the proposed duty to recontact embodies this "human vision" by advancing the principle that the clinical interpretation of "continuing expert care" can no longer be restricted to the medical treatment of disease but must be expanded to include a patient's informational needs. However, other equally compelling values and practical considerations must be taken into account.

First, if there is a lack of appropriate resources and qualified personnel, one must inquire how a geneticist or physician can reasonably and practically fulfill such a duty to recontact. This question seems especially appropriate, given that the recognition of this duty could represent a new, potentially inequitable, and onerous cause of action for medical negligence. Although a number of the suggestions proposed by Fitzpatrick et al. (1999), such as the use of Internet sites, appear to be very reasonable solutions, arguments have been voiced that a geneticist, at the risk of exposure to liability, has an obligation to ensure that not only the quality of the information, but also the manner of communication (e.g., language and terminology, taking into account cultural and socioeconomic differences) and the method of communication (e.g., telephone call or letter) (Sharpe 1994*a*; National Society of Genetic Counselors 1997) are reasonably appropriate to a patient's needs. Discussion and debate continue, for example, about how to effectively communicate health information on the Internet (Jadad and Gagliardi 1998; Kim et al. 1999).

Second, the fundamental objective and underlying rationale for the duty to recontact is that it will provide benefit and prevent harm. But is this operative assumption valid? What if recontacting a patient provokes adverse emotional and psychological responses? (Almqvist et al. 1997; Fitzpatrick et al. 1999). Aside from the fact that such responses could affect a patient's ability to appropriately understand the nature and implications of the new information (Sharpe 1994*b*), what of the impact on the patient and the family? Will the geneticist or the

physician have an obligation, and the required resources, "to provide appropriate psychological support" (Canadian College of Medical Geneticists 1997), "to help families and individuals recognize and cope with their emotional and psychological needs," and to "recognize situations that require psychiatric referral" (American Board of Medical Genetics 1997)? If the proposed duty to recontact is to become part of a geneticist's or a physician's duty of care toward a patient, it cannot operate independently of her or his other duties.

Third, the medical-genetics and genetic-counseling communities recognize that good patient care requires an individualized, patient-by-patient approach. Genetic diseases such as phenylketonuria, Huntington disease, cystic fibrosis, and neurofibromatosis represent distinct clinical problems and outcomes, with equally distinct patient needs on a short-term as well as on a long-term basis. One patient's response to a presymptomatic test result—or to the news of a new diagnostic or risk-clarification test—can be substantially different from another's. How is the duty to recontact to be applied practically, first for each of these diseases, and second on a patient-by-patient basis, given the prevailing value of nondirective counseling? More importantly, how will the duty to recontact be reconciled with a patient's fundamental right of autonomous decision making, including the right not to know (Ost D 1984; Yarborough et al. 1989; De Wert G 1992)? Will notes made at the end of a clinical record (Fitzpatrick et al. 1999) be sufficient to protect a patient's autonomy and values?

Given these concerns and risks, what practical benefit is to be gained by adding the duty to recontact to the already existing obligations to monitor, to provide appropriate aftercare, to refer, and not to abandon? Would it not be preferable—and more realistic—to resolve this issue, on a patient-by-patient basis, within the existing framework of these medical and legal obligations, especially with regard to the obligations of the geneticist or physician?

If the consensus, however, is to recognize some form of a duty to recontact, or at least an obligation to provide information to former patients, a solution may be found by returning to the underlying principles of the genetic-counseling therapeutic model of care. For nearly 25 years (Ad Hoc Committee on Genetic Counseling 1975), a fundamental objective of the genetic-counseling process has been to help patients to make the best possible adjustment, and to choose a course of action which seems most appropriate to them given their goals and ethical and religious standards. These principles recognize that the patient will play an integral role in the therapeutic process.

The patient, therefore, will have to accept a reasonable degree of responsibility, including the obligations to provide appropriate information (e.g., her or his family's medical history); to make a reasonable effort to understand the nature and implications of genetic information; and to describe his or her particular concerns, needs, expectations, and values. There appears to be no good reason why this long-standing concept of responsibility shared by the patient and the geneticist or physician should not equally apply to the duty to recontact.

The responsibility of the geneticist or physician, therefore, will be to discuss this issue with each patient, to receive instructions, and to keep reasonably up-to-date with all significant—and proven—research advances. The patient will have a corresponding obligation to contact the geneticist or the physician on a regular basis, such as once per year, for updates, and to request an appointment for clarification or for counseling, if required.

But, again, is this type of responsibility realistic and practically attainable, given the resources available to a geneticist or to a physician, especially with regard to qualified personnel? When one speaks of ethical values and moral obligations, one does not necessarily speak of absolute standards. One speaks of a choice among possible alternatives, with the knowledge that none of the available options may prove harmless. In a circumstance in which either course of action would appear to offer both benefit and harm, which course is to be given priority, and by whom?

Advocates of the duty to recontact argue that it should be recognized as a standard of care, because it exemplifies medicine's traditional values and objectives by providing the best opportunity for therapeutic benefit and the prevention of medical harm. This duty, however, has been given a higher priority despite the facts that (1) a former patient could suffer harm in the form of adverse psychological responses; (2) the geneticist or the physician could incur harm in the form of an inequitable and unreasonable exposure to legal liability for medical negligence; and (3) the duty may prove practically difficult, if not impossible, to fulfill. It is reasonable, therefore, to ask why the duty to recontact has been given priority, why its values have been deemed more valid, and who made this decision.

In 1994, I examined how a court of law would be likely to interpret professional accreditation standards and human/medical genetics literature with respect to a geneticist's duty of care for communication, informed consent, and psychological counseling for presymptomatic testing for Huntington disease (Sharpe 1994*a*, 1994*b*). My intent was to alert the medical-genetics and genetic-counseling communities to the implications that such standards of care could pose in terms of a physician's practical ability to provide such care in clinical- or primary-care service, as well as the potential expansion in causes of action for medical negligence.

The conclusion, which applies equally to this discus-

sion, stated that "the standard of care identified in this article has not been imposed by a court of law. It is the standard of care developed by geneticists and physicians. Debate as to its 'reasonableness' will have to be resolved by the medical genetics community" (Sharpe 1994*a*).

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Reply to Sharpe

To the Editor:

Mr. Sharpe correctly notes that in our article (Fitzpatrick et al. 1999) he was credited for considering the existence of a physician's duty of care toward patients (Sharpe 1994). His comments in this regard were indeed made in the context of Huntington disease, but, as we did not attribute to him *any* opinion on the duty to recontact, his position on this subject was not misrepresented, but simply omitted, from our discussion. We apologize to Mr. Sharpe and thank him for clarifying his position. The intention of our article was to report and discuss original research findings and not to present a detailed analysis of medical principles and legal obligations associated with a theoretical duty to recontact. It was our hope that our article would stimulate such a discourse, and we thank Mr. Sharpe for his insightful comments.

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The Choice to Have a Disabled Child

To the Editor:

What are the purposes of genetic testing, what are the principles guiding its use, and who should decide what tests should be available for what purposes? These familiar questions are raised in an unfamiliar context by a study reported recently in this journal (Middleton et al. 1998). Attitudes toward genetic testing were assessed among deaf people attending a conference in the United