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The Duty to Recontact: Attitudes of Genetics Service Providers

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Summary

The term "duty to recontact" refers to the possible ethical and/or legal obligation of genetics service providers (GSPs) to recontact former patients about advances in research that might be relevant to them. Although currently this practice is not part of standard care, some argue that such an obligation may be established in the future. Little information is available, however, on the implications of this requirement, from the point of view of GSPs. To explore the opinions of genetics professionals on this issue, we sent a self-administered questionnaire to 1,000 randomly selected U.S. and Canadian members of the American Society of Human Genetics. We received 252 completed questionnaires. The major categories of respondents were physician geneticist (41%), Ph.D. geneticist (30%), and genetic counselor (18%); 72% of the total stated that they see patients. Respondents indicated that responsibility for staying in contact should be shared between health professionals and patients. Respondents were divided about whether recontacting patients should be the standard of care: 46% answered yes, 43% answered no, and 11% did not know. Those answering yes included 44% of physician geneticists, 53% of Ph.D. geneticists, and 31% of genetic counselors; answers were statistically independent of position or country of practice but were dependent on whether the respondent sees patients (43% answered yes) or not (54% answered yes). There also was a lack of consensus about the possible benefits and burdens of recontacting patients and about various alternative methods of informing patients about research advances. Analysis of qualitative data suggested that most respondents consider recontacting patients an ethically desirable, but not feasible, goal. Points to consider in the future development of guidelines for practice are presented.

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Introduction

Advances in medical genetics are occurring at an exponential rate. As a result of progress in the Human Genome Project and in the elucidation of the genetic bases of cancer and common multifactorial diseases, the ability of genetics service providers (GSPs) to meet the population's needs for counseling and evaluation is becoming increasingly challenged. Added to the pressure on GSPs of serving clients for so many new indications is a growing awareness of another issue, the ethical and possibly legal obligation to recontact former patients when new developments occur.

From an ethical standpoint, among the situations in which a moral obligation to recontact patients may be considered to apply are (1) those in which a diagnosis had been suspected, but not made, and a new diagnostic test has been developed; (2) those in which a more accurate diagnostic and/or prognostic test, postnatal or prenatal, has been developed (e.g., from linkage to mutation detection); and (3) those in which new information may alter the prognosis or recurrence-risk estimates (Fletcher et al. 1985; Andrews 1991; Côté et al. 1995). Patients' knowledge of advances in the molecular genetic bases of their disorders may have great impact on their lives, affecting their psychological well being, reproductive options, employment decisions, and lifestyle choices such as marriage (Almqvist et al. 1997); in addition, there is a consensus in the medical genetics community that patients should have access to information about such advances.

From a legal perspective, 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) or that could cause them to choose another course of action, no matter how remotely probable (Pelias 1992). The duty of care was extended to include the duty to patients formerly in care (the "duty to recall"), in the California case *Tresemer v. Barke* (86 Cal. App. 3d 617 [1978]; 150 Cal. Rptr. 384 [1978]), in which a physician who had inserted a Dalkon Shield (A. H. Robins Co.) intrauterine contraceptive device was held liable for failing to warn the woman 3 years later

of its newly discovered health risks (Berg and Hirsh 1980). To date, no legal obligation for recontacting former patients when new genetic information becomes available has been established, but some have argued that such an obligation could find support in U.S. courts (Andrews 1991; Pelias 1991).

Little information is available on the implications of formalizing a duty to recontact with regard to the provision of genetics services. Establishing such liability could mean that any one visit to a geneticist could result in a perpetual duty of care for the provider, leading to burdensome requirements for the storage and retrieval of information (Hannig et al. 1993) and to the diversion of funds for case review and management (Côté et al. 1995) that may be better spent in other areas. Moreover, as Andrews (1991) reminded us, for many physicians in other specialties, recontacting patients when new information is available to aid their condition is not typical practice; such information is imparted during routine follow-up care but does not extend to former patients. One may argue that geneticists should be able to make the same distinction between their responsibilities to patients currently being followed up and to those discharged from care. Finally, one may argue that the geneticist, in the role of the consultant, has neither the right nor the obligation to recontact former patients directly and that the responsibility for keeping patients up to date rests with primary care physicians.

Is keeping former patients informed about research advances a desirable goal? If so, should responsibility be placed solely on GSPs? Might other health care providers or societal groups, such as the media, genetic support groups, and/or patients themselves, share some of this responsibility? As a first step in the exploration of this complex issue, we undertook to document the attitudes of GSPs toward (1) the locus of responsibility in keeping patients informed of new developments in molecular genetics and (2) the possible considerations, both ethical and logistical, of addressing the duty to recontact in the future.

Subjects and Methods

In a previous study (Huggins et al. 1996), 43 adult patients and the parents of patients with a diagnosis of neurofibromatosis (NF) type 1, who were followed at the Hospital for Sick Children in Toronto, completed a questionnaire that assessed their attitudes toward the duty of various health professionals to recontact them in the event of improvements in the ability to diagnose NF or to conduct prenatal testing, predict the clinical course, or provide treatment for this condition. Additional questions solicited opinions about the responsibility of both patients and health care providers to stay informed about research advances.

To survey the attitudes of GSPs toward the duty to recontact, we developed a questionnaire asking many of the same questions and added another series of questions about the duty to recontact in general. The current study questionnaire consisted of the following four parts:

1. "Personal Background": five questions designed to assess the professional's demographic characteristics and amount and type of clinical activity performed.
2. "The Duty to Recontact: Advances in Neurofibromatosis Type I Research": eight questions posed previously to NF patients and family members, the responses to which were compared to those of the patient population studied previously.
3. "The Duty to Recontact: Current Practice": two questions designed to assess whether respondents are already recontacting patients in their practice.
4. "The Duty to Recontact: Theoretical Considerations": five items eliciting opinions as to the locus of responsibility in keeping patients informed about research advances; that is, whether recontacting patients should be formalized into a standard of care, the most important considerations in determining whether or when recontacting a patient would be appropriate, and the merit of various possible informal methods of ensuring that patients are kept informed about future advances in research.

The questions for sections 2–4, as they appeared on the questionnaire, and details of how respondents were instructed to answer them are presented in Results. Comments were requested for many of the questionnaire items. Such qualitative data were solicited to help interpret and explain any statistically significant quantitative observations and to enrich our understanding of the opinions held by the GSP respondents.

A pilot study using the questionnaire was performed with 20 volunteer genetics professionals and trainees from the Hospital for Sick Children and the University of Michigan. The questionnaire was revised subsequently on the basis of the feedback received. The revised questionnaire, together with an explanatory cover letter and a return envelope without postage, was mailed to 1,000 randomly selected members of the American Society of Human Genetics (ASHG) who live in the United States ($n = 940$) or Canada ($n = 60$). Participants in the pilot study were excluded. Respondents had 4 wk to return the questionnaire, and responses were anonymous. On receipt of the completed questionnaires, items were coded, and the responses were entered into the computer program Microsoft Excel 5.0, for statistical analysis.

Results

We received replies from 267 individuals. Of these, 10 indicated that they would not be participating, 1 returned a letter explaining his opinions, and 4 returned their questionnaires after the deadline; these 15 were not counted statistically. The remaining 252 completed questionnaires were counted, yielding a response rate of 25%.

Personal Background

Respondents from the United States numbered 234 (93%), and those from Canada numbered 18 (7%). These response numbers corresponded closely to the proportion of questionnaires mailed to the two countries (94% and 6%, respectively). Of all the respondents, 72% stated that they see patients; 12% of all respondents work in a research laboratory, 21% work in a laboratory that performs both research and clinical service, 17% work in a service-only or diagnostic laboratory, and the remaining 49% do not work in a laboratory. With respect to position, the major categories of respondents were physician geneticist (41%), Ph.D. geneticist (30%), and genetic counselor (18%). Ph.D. geneticists included professionals involved in teaching, research, and/or clinical activities. The remaining 11% of respondents were assigned various other categories, such as genetics nurse, graduate student, or laboratory technologist. Our sample appears to be skewed, with a higher proportion of respondents involved in clinical activities, compared with the ASHG membership as a whole. In 1997, of the 76% of ASHG members who had submitted membership-profile surveys, 11% were genetic counselors, 26% held M.D. degrees, and 32% held Ph.D. degrees; we considered the latter two percentages to be loose approximations of the proportions of physicians and Ph.D. geneticists (Smith 1997). In our view, this skew in the distribution of respondent characteristics is a reflection of the clinical relevance of the topic under consideration.

The Duty to Recontact: Advances in Neurofibromatosis Type I Research

"Who is responsible for ensuring that patients and their families stay informed about advances in research?"—Respondents were asked to select a number from a scale of 1–5, in which 1 represented patient responsibility, 5 represented health care–provider responsibility, and 2–4 represented some degree of shared responsibility for keeping patients informed. The question was asked as it pertained to four types of research advances: diagnostic testing, prenatal diagnosis, prediction of the progression of symptoms, and treatment of NF. Overall, respondents indicated that responsibility for keeping patients informed about research advances should be shared, with health care providers having slightly more responsibility than patients. On the "responsibility scale" of 1–5, the mean responses for the four types of research advances were 3.2, 3.4, 3.4, and 3.6, respectively, as shown in figure 1. These values were not significantly different from those based on the response of the NF families studied previously (two-sample z-test, $P < .05$). Because the NF families studied previously were from Canada but most of our GSP respondents were from the United States, we performed a separate analysis of the subset of GSP respondents from Canada ($n = 18$). Among this group, the mean responses for the four types of research advances were 3.1, 3.3, 3.5, and 3.6, respectively. The sample size for the Canadian respondents was not sufficiently large to allow comparisons with the previously studied sample of patients; however, the results appear to follow a similar trend.

"To what extent would each of the following health professionals have a duty to recontact patients if there were an advance in research?"—In a second series of questions, we asked subjects the extent to which various types of health professionals have a duty to recontact. The categories of health professional were family doctor, clinical geneticist, genetic counselor, general pediatrician, other consultant physician(s)—such as neurologist, ophthalmologist, or surgeon—and other. Respondents were asked to select a number from a scale of 0–5, in which 0 represented no duty and 5 represented a great degree of duty, for each type of health professional. Once again, the question was asked as it pertained to four types of research advances: diagnostic testing, prenatal

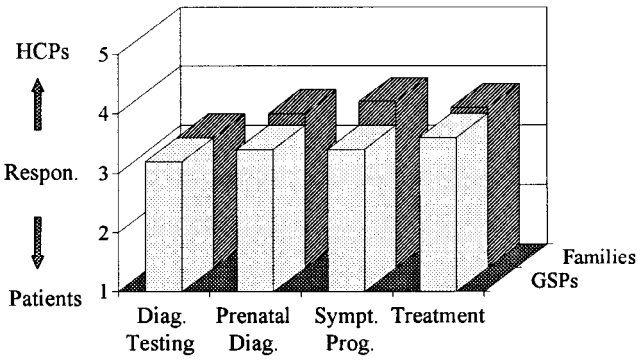

Figure 1 Mean response to the question "Who is responsible for ensuring that patients and their families stay informed about advances in research?" The question was asked of GSPs in this study and NF family members in a previous study, and it applied to research advances in four areas: diagnostic testing, prenatal diagnosis, prediction of the progression of symptoms, and treatment for NF. A scale of 1–5 was used, in which 1 = patient responsibility and 5 = health care–provider responsibility. HCPs = health care providers.

diagnosis, prediction of the progression of symptoms, and treatment of NF.

The mean responses to these questions are depicted in figure 2. For each type of research advance, GSP respondents assigned the highest degree of duty to clinical geneticists and the second highest degree of duty to either genetic counselors or family doctors. Among the NF family members studied previously, the highest degree of duty was assigned to clinical geneticists, and the second highest degree of duty was assigned to genetic counselors, for each type of research advance. Comparison of the results from the two samples revealed that, for each category of health professional and for each type of research advance, NF family members assigned a higher mean degree of duty to the health professionals than did the GSPs. For the category of family doctor and hypothetical research advances in diagnostic testing (fig. 2*A*), prediction of the progression of symptoms (fig. 2*C*), and treatment (fig. 2*D*), differences between sample means were not statistically significant; for all other categories and each type of research advance, differences were significant (two-sample z-test, $P < .01$). We note that, for research advances in prenatal diagnosis (fig. 2*B*), 46 respondents appropriately added obstetrician/gynecologist in the "other" category, assigning a mean degree of duty of 4.3. However, this could not be factored into the comparison of results for the other clinical scenarios. When the results for the four types of research advances were compared, the highest degree of duty was assigned, by both groups, to hypothetical advances in the treatment NF.

Again, the sample size of Canadian GSP respondents ($n = 18$) was too small to draw conclusions about how their opinions compared with those of the (Canadian) NF family members studied previously. Subjectively, however, they followed similar trends. Canadian GSP respondents assigned the highest degree of duty to clinical geneticists, in three of the four categories of research advances; they assigned a lower mean degree of duty to health professionals than did the NF family members,

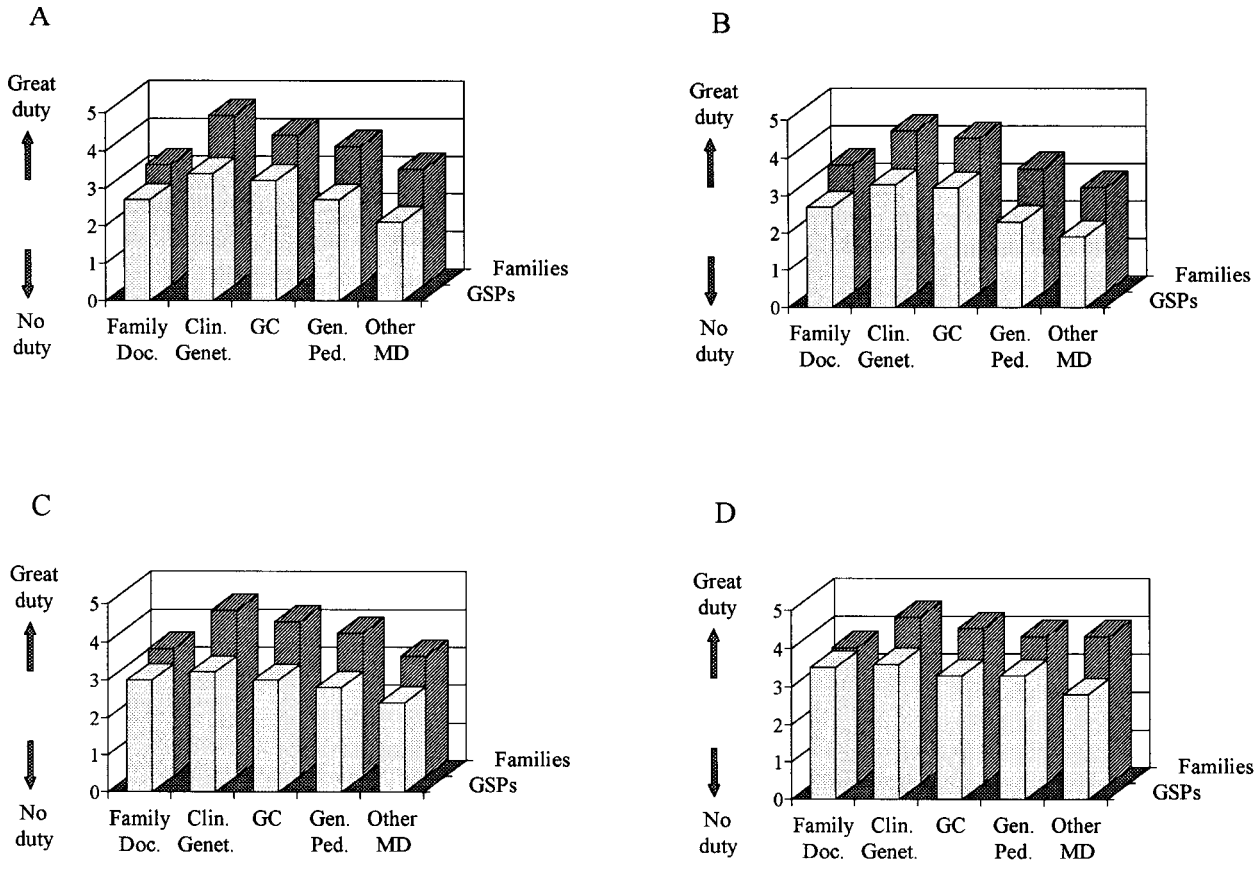

Figure 2 Mean responses to the question "To what extent would each of the following health professionals have a duty to recontact patients if there were an advance in research?" The question was asked of GSPs in this study and NF family members in a previous study, and it applied to research advances in four areas: diagnostic testing (*A*), prenatal diagnosis (*B*), prediction of the progression of symptoms (*C*), and treatment for NF (*D*). A scale of 0–5 was used, in which 0 = no duty and 5 = a great degree of duty. "Doc." = doctor, "Clin. Genet." = clinical geneticist, GC = genetic counselor, "Gen. Ped." = general pediatrician, and "other MD" = other consultant physician.

for each category of health professional and for each type of research advance; and they assigned the highest degree of duty overall for hypothetical advances in the treatment of NF.

The Duty to Recontact: Current Practice

"Have you personally ever recontacted a patient regarding research advances?"—Sixty-one percent of respondents answered yes, 32% answered no, and 7% answered that they did not recall.

"Has your department/unit established a formal system for the specific purpose of recontacting patients about research developments?"—Thirteen percent of respondents answered yes, 77% answered no, and 10% answered that they did not know. Comments were requested for this question, and 63 (25%) respondents provided them. The majority of comments from those answering yes specified existing systems for recontacting patients. Responses revealed a wide variation in interpretation of the word "formal": "Yes, we ask patients to contact us annually"; "yes, continually updated database, by case, by condition, and quarterly questionnaires to patients in on-going therapy." The majority of comments from those answering no served to justify their response: "We have 30,000 charts going back 25 years! We have neither the staff nor time to do this systematically!!" "Who will pay? Unless this service is part of capitation or managed care it won't happen." One respondent described actual experience with recontacting patients: "No. Recontact was a waste of time. Very little response to the letters and 50% of the patients had moved. Patients must recontact at a defined interval."

The Duty to Recontact: Theoretical Considerations

The hypothetical duty of GSPs was investigated separately from the hypothetical responsibility of patients and without reference to a particular genetic disorder or type of research advance.

"How much of an ethical or moral duty do genetics service providers have to recontact former patients?"—On a scale of 1–5, in which 0 represented no duty and 5 represented a great degree of duty, the mean response was 3.4. The clinical GSPs felt that they have some duty to keep patients informed about research advances. Space for comments was not provided for this question, but a small number of respondents expressed concerns such as the following: "Unless it becomes a legal duty, the ethics and morality won't carry much weight in today's medical climate."

"How much responsibility do patients have to keep in contact with genetics service providers?"—On a scale of 1–5, in which 1 represented no responsibility and 5 represented a high degree of responsibility, the mean response was 3.9. The degree of responsibility for maintaining contact that the GSPs assigned to patients was higher than the degree of duty they assigned to themselves.

"Should recontacting patients about research advances be the standard of care for clinical genetics service providers?"—Forty-three percent of respondents answered yes, 46% answered no, and 11% indicated that they did not know. Comments were requested for this question also, and 86 respondents (34%) provided them. One common theme among the comments from those answering yes was philosophical support for recontacting patients: "What other way is there to serve patients appropriately"; "it's part of the job description"; "recontact is a right and a responsibility for both patients/families and physicians/laboratories." However, most of the comments from those answering yes served to qualify their responses: "Funding needs to be provided for this responsibility by the government/public 'friends'"; "but a follow up system which works automatically and easily must be available for this to work in any realistic fashion"; "one question will be when is the research secure enough to recontact." Thus, many respondents who support the idea of recontacting patients would only do so under certain circumstances. Comments from those answering no to this question are typified by the following: "I believe in personal responsibilities. To place this burden on health care providers is unfair." "You use legal terms 'duty' and 'standard of care.' Translate: Do it or my trial lawyers groups will sue." "We completely lack resources. No other specialty does it." Those answering yes to the question included 44% of physician geneticists, 53% of Ph.D. geneticists, and 31% of genetic counselors; answers were statistically independent of position or country of practice but were dependent on whether the respondent sees patients. Forty-three percent of the respondents who *do* see patients felt that recontacting patients should be the standard of care, whereas 54% of those who *do not* see patients felt that it should (χ^2 independence test, $P < .05$).

Ethical, Legal, and Practical Considerations

Subjects were asked to consider various ethical, legal, and practical considerations that might be significant if a system for recontacting patients about research advances were to be established. They were asked to indicate whether they felt that a particular issue would be important in determining whether or when recontacting a patient would be appropriate. Responses are shown in table 1. Overall, more respondents identified as important the possible benefits to patients, compared with the benefits to GSPs. The most frequently cited possible burden for patients was anxiety and stress; for GSPs, it was the staff time required. This question seemed to have

Table 1

Possible Considerations Involved If a Formal System for Recontacting Patients Were Established

	Possible Burden	Percentage of Respondents	Possible Benefit	Percentage of Respondents
Patients	Anxiety and stress	82	Improved care (follow-up)	100
	Intrusion of privacy	66	Reduced uncertainty	92
	Concerns about health insurance	81	Renewed hope for the future	92
	Concerns about life insurance	76		
GSPs	Staff time required	90	Better organization of workload	54
	Cost of information storage and retrieval (e.g., hardware/software)	79	Improved patient care (e.g., consistent follow-up)	94
	Ensuring fairness for all patients	80	Reduced risk of litigation	63
	Unlocatable patients	82		

been unclear to many respondents, and, therefore, further statistical analysis was not performed. However, many respondents contributed their own items to the lists of benefits and burdens, which we considered to be informative. For example, "confusion" and "ambiguity" were added as possible burdens for patients, and "providing some sense of control and participation in health care" and "empowers patient" were added as possible benefits. "Increased risk of litigation" and "defining how much effort is sufficient" were added as possible burdens for GSPs, and "seen as having something besides 'talk' to offer" and "fits into more familiar 'medical' model" were added as possible benefits.

Other Methods of Ensuring That Patients Stay Informed

As an alternative to a formal system for recontacting patients, there may be informal, more feasible methods of keeping families up to date about research developments. From a list of six such methods, subjects were asked to choose two that they felt would be the most effective. These methods and their relative appeal to respondents are presented in table 2. No particular method was seen as being far superior to any other. Responses could be grouped into two broad categories—popular options and less popular options. Popular methods included suggesting that the patient call the GSP's office or that the family physician re-refer patients periodically and informing relevant genetics support groups. Respondents demonstrated little confidence in the media and other types of health care providers, for the dissemination of information about advances in genetic research.

Discussion

The concept of a possible ethical, moral, or legal duty of clinical GSPs to recontact former patients about advances in research has received considerable attention in recent years (Berg and Hirsh 1980; Andrews 1991; Pelias 1991, 1992; Sharpe 1994; Côté et al. 1995; Huggins et al. 1996; Patenaude 1996; Almqvist et al. 1997). For some time research and/or clinical service laboratories have been grappling with the issue of so-called look-back testing—that is, the retesting of previously obtained samples with newly available probes, to identify mutations (Hannig et al. 1993). Position papers on recontacting patients are being prepared independently by the Look-Back Subcommittee of the Social, Ethical, and Legal Issues Committee of the American College of Medical Genetics (K. Hirschhorn, personal communication) and by the Ethics and Public Policy and Clinical Practice Committees of the Canadian College of Medical Geneticists (F. C. Fraser, personal communication). This study, however, is the first to document the opinions on this issue of a cross section of GSPs.

Overall, the opinions of the GSPs showed trends similar to those of the NF family members studied previously. Both groups considered keeping patients informed a shared responsibility, and both identified GSPs as having the most duty to keep patients informed, among various types of health professionals. In addition, both groups were able to make some distinction in the duty to recontact in different clinical situations, assigning the highest degree of duty for hypothetical advances in the treatment of NF. Our results suggest that, in the future, patients and GSPs may enter into an effective partnership in the pursuit of the shared goal of keeping patients informed. As to the significantly greater degree of duty assigned by the NF family members to the various health professionals, compared with that assigned by the GSPs, we note that interpretation of our results in this section is limited by the fact that the sample of NF patients and family members was drawn from a Canadian population, whereas the vast majority of the current study sample was drawn from the United States. An interesting topic to explore in future research might be whether such differences in attitude are universal among patients versus GSPs or whether opinions on this issue vary with sociological differences in consumerism and in the economics of health care, between the two countries. Subjective analysis of our results from the Canadian GSP

Table 2

Most Effective Informal Methods of Ensuring That Patients Stay Informed about Research Advances

Method	No. of Respondents
Asking patients to call GSP's office at periodic intervals (e.g., once per year)	104
Asking patients to call GSP's office if their clinical status or circumstances change (e.g., if they become pregnant or if new symptoms develop)	92
Informing the media about specific research advances	45
Informing relevant genetics support groups about research advances	92
Informing other health care providers (e.g., community physicians) about specific research advances or new technologies	43
Educating other health care providers (e.g., community physicians) about the rapid pace of genetic research and the need to re-refer patients for updated information	86
Other	16

NOTE.—Respondents were asked to choose two methods, and not every respondent answered this question. Responses with more than two methods selected were not counted.

respondents, however, which revealed opinions similar to those of the U.S. respondents, suggests that such differences in attitude between patients and GSPs may be universal. If it is true that patients assign a greater degree of duty to health professionals than health professionals assign to themselves, this might suggest a potential for litigation: are patients with unmet expectations more likely to sue than those whose expectations match those of the providers of the delivery of care?

More than half of the respondents have recontacted a past patient about a research advance, but only 13% indicated that they have a formal system in place for doing so. The many comments added in justification of not having a formal system suggest that, although GSPs may agree, in principle, that recontacting patients is indicated under certain circumstances, they perceive significant barriers to doing so systematically and view implementation of a formal duty to recontact as requiring a major investment of resources.

There was no consensus regarding whether recontacting patients should be the standard of care for clinical GSPs, with 46% of respondents answering yes, 43% answering no, and 11% answering that they did not know. However, analysis of demographic correlates to a yes opinion demonstrated a trend, suggesting that those with more clinical involvement are more likely to feel that recontacting patients should *not* be the standard of care.

Among respondents, there was also a lack of consensus about the various possible benefits and burdens of recontacting patients. One finding worthy of note, however, was that the GSPs perceived anxiety to be one of the most important drawbacks, for patients, of being recontacted. With regard to the patient's point of view, the desirability of being contacted systematically when new information becomes available is unknown. Although there is some evidence that patients feel that new genetic-research findings need to be made more readily available to them (Buxton and Pembrey 1996), there also is evidence that recontacting patients may renew patient anxiety (Almqvist et al. 1997). Further studies of patient attitudes are warranted, to determine the extent to which this perception is justified.

Our finding that the degree of responsibility for keeping contact that the GSPs assigned to patients was slightly higher than the degree of duty they assigned to themselves suggests that, in addressing the possible duty of keeping patients informed in the future, a policy of putting more of the onus on the patient may be acceptable for GSPs. This is supported by our finding that methods of keeping patients informed that put the onus on the patient were popular, whereas methods involving third parties, such as other health professionals or the media, were less popular. Interestingly, despite the fact that many respondents identified the family doctor as having a relatively high degree of duty to keep patients informed about advances, the option of informing other health care providers about advances was among the less popular alternative methods for doing so. Perhaps by asking about the *duty* of various health professionals to keep patients informed separately from the *effectiveness* of various methods of doing so, we revealed an inherent inconsistency in the opinions of the GSPs. If GSPs consider family practitioners to be the most logical, but not the most effective, facilitators of the transmission of information about research developments, perhaps a future task for GSPs would be to implement measures to optimize this method of disseminating information.

We conclude that, although many GSPs support the idea of recontacting patients about advances in research, they perceive that such an endeavor would be impossible within the confines of the current health care system. On the other hand, the social, psychological, and ethical implications of medical genetics may extend beyond those of many other areas of medicine (Andrews 1991), and patient expectations may dictate, in the future, pro-

vider responsibility through litigation. GSPs may wish to work proactively toward some method of addressing this issue, either for ethical reasons or to protect themselves in court. The development of guidelines for clinical practice that account for the expectations of patients may serve this purpose.

Fletcher et al. (1985) proposed the establishment of guidelines for clinical genetics when consensus exists, emphasizing the need to consolidate what has been learned about difficult moral choices. In their view, the emergence of guidelines is a natural consequence of the evolution of a field that has achieved specialty status in medicine. Grimshaw and Russell (1993) conducted a systematic review of the effect of clinical guidelines on medical practice and found that 55 of 59 published evaluations that met defined criteria for scientific rigor yielded significant improvements in the process of care after their introduction. They concluded that explicit guidelines do improve clinical practice, especially if the development strategy is, among other factors, internal to the specialty. Brook (1996) suggested that, for guidelines to be maximally effective, they must be based on the best synthesis of scientific evidence and expert judgement. On the basis of this published experience and the results of this study, we propose an approach to the establishment of practice guidelines for recontacting former patients, for GSPs.

We suggest that GSPs consider incorporating the following strategies into their practice. First, providers might ask patients to accept more responsibility for keeping informed about research advances. At the close of a genetics consultation, GSPs might take a moment to engage the patient in a brief discussion of the issue of keeping patients up to date and the lack of resources available to GSPs to do so. Simply mentioning this issue may engender, among patients, some acceptance of responsibility in the form of a verbal agreement or at least may educate them to the point that their expectations of being recontacted are lowered. GSPs might ask that patients contact them periodically (e.g., every 2 years) or in the event of a change in clinical status or pregnancy, for news of research developments. Consistent efforts may be made to provide patients with Internet sites and membership information for active support and/or research societies and to encourage them to join such groups so that they may receive newsletters and updated information. Identification of patients who would prefer not to be recontacted and documentation, in the chart, of such informed refusal would be equally important.

Second, GSPs might increase their efforts to improve the continuing education of and communication with primary care providers so that they will be better equipped to accept more responsibility in this area. Primary care providers in urban centers may have access to in-services, conferences, and other continuing-education opportunities and may know where to refer patients for genetics services, but this may not be true in more-rural areas. Local and/or regional bulletins directed to referring primary care providers, sent by either regular or electronic mail, may be effective, particularly if kept to one or two pages and presented in point form. Standard paragraphs may be added in boldface type at the end of clinic notes, to remind referring providers of the rapid pace of genetics research and of the need to re-refer patients for updated information if indicated.

Third, GSPs might establish working groups to delineate priorities regarding the types of research developments, such as those that affect treatment or prevention, that are most important to communicate to patients. Patients may willingly accept more responsibility for staying up to date if GSPs agree to recontact them when a research advance would alter their prognosis. Finally, we suggest that those professionals who would be most affected by a policy for recontacting patients be intimately—if not solely—involved in the process of developing guidelines for clinical practice.

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References

Almqvist E, Adam S, Bloch M, Fuller A, Welch P, Eisenberg D, Whelan D, et al (1997) Risk reversals in predictive testing for Huntington disease. Am J Hum Genet 61:945–952

Andrews L (1991) Legal aspects of genetic information. Yale J Biol Med 64:29–40

Berg D, Hirsh HL (1980) Duty to recall. South Med J 73: 1041–1044

Brook RH (1996) Practice guidelines: to be or not to be. Lancet 348:1005–1006

Buxton JL, Pembrey ME (1996) The new genetics: what the public wants to know. Eur J Hum Genet Suppl 4:153

Côté JP, Klimek ML, Johnson CL (1995) Do genetic clinics have a legal/ethical duty to recontact their patients when new information arises? Am J Hum Genet Suppl 57:A293

Fletcher JC, Berg K, Tranøy KE (1985) Ethical aspects of medical genetics: a proposal for guidelines in genetic counseling, prenatal diagnosis and screening. Clin Genet 27:199–205

Grimshaw JM, Russell IT (1993) Effect of clinical guidelines on medical practice: a systematic review of rigorous evaluations. Lancet 342:1317–1322

Hannig VL, Clayton EW, Edwards KM (1993) Whose DNA

is it anyway? Relationships between families and researchers. Am J Med Genet 47:257–260

Huggins M, Hahn C, Costa T (1996) Staying informed and recontacting patients about research advances: a study of patient attitudes. Am J Hum Genet Suppl 55:A335

Patenaude AF (1996) The genetic testing of children for cancer susceptibility: ethical, legal and social issues. Behav Sci Law 14:393–410

Pelias MZ (1991) Duty to disclose in medical genetics: a legal perspective. Am J Med Genet 39:347–354

——— (1992) The duty to disclose to relatives in medical genetics: response to Dr. Hecht. Am J Med Genet 42: 759–760

Sharpe NF (1994) Psychological aspects of genetic counseling: a legal perspective. Am J Med Genet 50:234–238

Smith ACM (1997) Secretary's report. Presented at the annual business meeting of the American Society of Human Genetics. Baltimore, October 27