Duty to Recontact

Description: An article discussing the duty to recontact patients who may benefit from additional knowledge

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The continuing expansion of knowledge about genetics and genetic diseases creates unusual circumstances with respect to keeping patients informed about new advances in laboratory and clinical genetics. Information conveyed in past counseling sessions may change radically as new discoveries are documented. What then are the responsibilities of professionals, including both primary care providers and specialists in medical genetics, when important innovations may have a significant effect in the lives of patients? And what is the role of patients in contributing to the success of the professional-patient relationship?

Three major ethical issues have a direct bearing on interactions between professionals on the one hand and patients on the other. First, professionals are bound to respect the personal autonomy of patients, or the right of patients to make their own choices about their healthcare. Second, professionals are bound to respect the personal privacy of patients so that the private sphere of the patients is entered only with their consent. Third, professionals are held to the ethical principle of doing no harm in professional-patient interactions.

When important new information becomes available, the primary care provider and the professional geneticist may become legally obligated to recontact patients for further counseling. To be sure, this issue has not yet been litigated in the practice of medical genetics. However, 2 precedents in the common law still may be argued by analogy on the question of a duty to recontact in medical genetics. These cases involved a 5-year delay in notifying a patient cohort about the dangers of diethylstilbestrol and a failure for 7 years to recontact a patient about the dangers of the Dalkon shield intrauterine contraceptive device. In both cases, the courts decided in favor of the plaintiff-patients.
Common Law Precedents for Duty to Recontact

**Mink v. University of Chicago:** In the 1950s, the University of Chicago held a large clinical trial using the medication diethylstilbestrol (DES). DES had been prescribed previously in Europe to prevent miscarriage but had not been fully evaluated in the United States. Half of all pregnant women at the University Lying-In Hospital were given DES. Half were not. None of the women were informed about the experiment. In 1971, an article published in the *New England Journal of Medicine* cited a positive correlation between clear-cell adenocarcinoma and in utero exposure to DES. Pregnant women who were given DES at the University of Chicago were not notified of their exposure and the potential consequences until 1975-1976. Three women later filed suit against both the manufacturer of DES, Eli Lilly, and against the University of Chicago. To learn more about this case, visit an online excerpt from *Women and Health Research: Ethical and Legal Issues of Including Women in Clinical Studies, Volume 1* [2](1994).

**Tresemer v. Barke:** A woman was fitted with an intrauterine device (IUD). At the time, negative health effects caused by the device had not been established. After it became evident that the IUD carried with it significant health risks, the patient's physician did not recontact her with updated information. The patient later sued her physician. For more information about this case, visit the following medical malpractice case summary [3].

In order to provide benefits for patients and favorable practice circumstances for professionals, a growing minority of geneticists is urging the recognition of reciprocity in the professional-patient relationship. The professional assumes the obligation of keeping information and counseling current and complete. However, the patient assumes the obligation of contacting the professional for appointments for intermittent updates. Similarly, the patient assumes the responsibility for keeping the professional informed about contact information, including changes of address and telephone. These reciprocal responsibilities will create a balance in the relationship that will provide advantages for both parties. Discussing and establishing this reciprocity should take place early in the relationship, with assurances that both parties have a mutual understanding of the issues. The terms and understanding of the reciprocal relationship should be clearly documented in clinic notes, on consent forms, and in clinic letters that are sent to referring physicians as well as patients.

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