

Preface

I was sitting at the dining room table, eating brownies and brainstorming about my future with my sister, when the old, familiar question came up: What do you want to be when you grow up? That is not an easy question for a 20-something-year-old with two children to answer. Darwin's finches and speciation were my favorite subjects in graduate school. I had done laboratory work, and decided that it wasn't for me. The options for someone with a Master's degree to work in genetics outside the laboratory in the 1960s were limited. Go to medical school was one suggestion I heard. As I finished cleaning my plate, I thought about it. Medical school was a big commitment of time and energy, and then what could I do once I finished? That was about the time that the *New York Times* published an article highlighting the new Sarah Lawrence College training program in human genetics. I could teach at that program if I had a medical degree. Wow! A light bulb went on in my brain. I won't teach those students; I'll be one of them! My future was sealed.

In the context of medical care specialty professions, genetic counseling is the newcomer at the table. Dr. Melissa Richter created the role and directed the first training program at Sarah Lawrence College in 1969.¹ The profession of genetic counseling was conceived as a method for delivering genetic counseling and testing services more efficiently to patients with genetic disorders. The field of human genetics was beginning to identify and understand a growing number of disorders. The role of a patient advocate, that of helping people understand the medical and genetic information being provided, was seen as a needed addition to the medical genetics team. I came to genetic counseling relatively early, having seen that article in the newspaper. I graduated from Sarah Lawrence College in 1974.

In 1975, the *ad hoc* Committee on Genetic Counseling of the American Society of Human Genetics (ASHG) defined genetic counseling as:

... a communication process which deals with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to (1) comprehend the medical facts, including the diagnosis, probable course of the disorder, and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the options for dealing with the risk of recurrence; (4) choose the course of action which seems to them appropriate in view of their risk, their family goals, and their ethical and religious standards, and to act in accordance with that decision; and (5) make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder.²

This is the statement that defined our profession until relatively recently, when an updated definition was published by a Workgroup of the National Society of Genetic Counselors (NSGC).³

Training programs for genetic counselors are at the Master's Degree level in human genetics and/or genetic counseling. Since the first training program began at Sarah Lawrence, the number of programs in the United States and Canada had expanded to 30 in 2006.⁴

Practitioners usually turn to colleagues for support when professional issues or questions arise. Genetic counselors practicing in the 1970s felt the need for an organized way to address these common issues. A professional society was considered the best way to meet these needs, to enhance communication among genetic counselors and to promote the profession.

A group of counselors met at Sarah Lawrence College to discuss forming such a professional organization. One of our first challenges was to choose the title for our work and decide how we would address ourselves. Various titles were being used at the time: genetic associate, genetic assistant, genetic counselor. The process of defining ourselves was not as painless as it may sound. We had long discussions among ourselves and with our medical colleagues. We finally agreed to call ourselves genetic counselors. The name of our future organization was to be the National Society of Genetic Counselors, and the *ad hoc* Committee to Form the National Society of Genetic Counselors (NSGC) was established. As a member of that first committee, I worked on the by-laws and membership guidelines. I consider myself a founding mother of the NSGC, which was incorporated in 1978.

As the fields of medical genetics and genetic counseling continued to mature, the need to establish standards for practitioners and for their training was recognized by members of the genetics community. Certification and accreditation processes were developed. Medical geneticists, clinical geneticists and genetic counselors were included in the certification process that was established by the American Board of Medical Genetics (ABMG).

The first group of candidates sat for the board certification examinations in the winter of 1981. As is still the case, everyone took the same general genetics examination, and then sat for a second examination in a specialty field. Genetic counselors sat for a specialty examination in genetic counseling. There was no grandfathering of practitioners for experience or longevity. No one was exempt from the certification examinations. It was strange to sit in the same room, taking the same examination, as the men and women who had written the genetics books we all had to study.

Over time it became clear to the ABMG that recognition by the AMA as a specialty board would enhance the status of medical genetics. In order to meet the requirements, the ABMG would no longer be able to certify anyone who did not have a doctoral degree. The ABMG had to withdraw from certifying genetic counselors, and the American Board of Genetic Counseling (ABGC) was formed in 1993. The ABGC now has the sole responsibility of certifying genetic counselors and for accrediting graduate genetic counseling training programs. As the genetic counseling profession has continued to mature and grow, so have the visibility, responsibility and liability of genetic counselors.

During the early years when genetic counseling was establishing itself as a recognized profession, the legal profession was using the tort liability system as a means to aid the consumer. Tort law, of course, has been available to individuals for centuries. It was transformed, however, by a number of legal theorists who believed that consumers were unaware of the risks they took and were settling for less safety from products and healthcare than they should. The costs of preventing accidents and of paying for those accidents that do occur, these theorists suggested, should come from the manufacturers of goods and the providers of health care. Their intended goal was to deter substandard manufacturing and medical practice by requiring that compensation be paid to individuals harmed by faulty products and to patients wrongfully injured by healthcare providers.⁵

Prior to the early 1960s, malpractice litigation was very rare. The number of tort litigation rates rose dramatically in the 1970s. Figure 1 illustrates the rising numbers of lawsuits and claims against physicians since 1970. Not only has the number of cases filed increased since that time, but the damages awarded in those cases have increased as well.⁶

Figure 2 illustrates the increased amount of jury awards and settlements between 1993 and 2000. As can be seen in the figure, the median size of the damages awarded to plaintiffs more than doubled over the years. Total payouts reported by members of an insurance trade association can be seen in Figure 3. Payments of \$1 million or more increased from 3% to 8% of the total claims paid. One of the outcomes of this system has been an increase in price of some goods and a decline in the availability of some services. The question has now become how a system that was developed to increase safety and deter dangerous practices could result in a burden on those who work to help others.

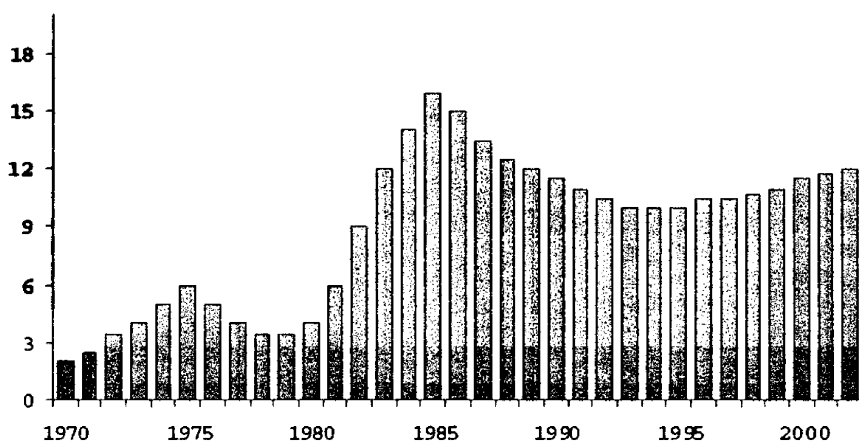


Fig. 1 Conceptual trend in the number of lawsuits and claims against physicians synthesized from the AMA data and other resources.

Source: From: Bovbjerg, R.R., and Bartow, A. (2003). *Understanding Pennsylvania's Medical Malpractice Crisis: Facts About Liability and Insurance, the Legal System, and Health Care in Pennsylvania*. Pew Project on Medical Liability.

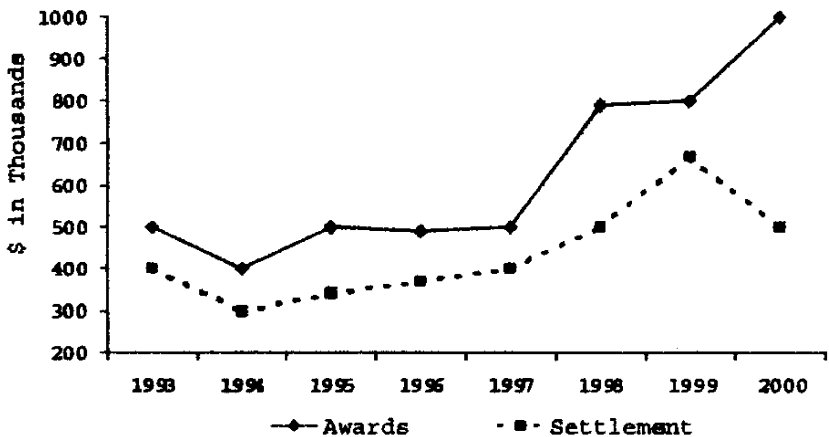


Fig. 2 Reported U.S. median medical liability awards and settlements.
 Source: From: Bovbjerg, R.R., and Bartow, A. (2003). *Understanding Pennsylvania's Medical Malpractice Crisis: Facts About Liability and Insurance, the Legal System, and Health Care in Pennsylvania*. Pew Project on Medical Liability.

A comprehensive research study on medical error and malpractice litigation done in 1990 by the Harvard Medical Practice Study demonstrated a lack of agreement between the occurrence of actual medical negligence and the initiation or resolution of legal claims. One out of eight occurrences of negligence (as judged by the study team) led to malpractice lawsuits. Half of the plaintiffs in those lawsuits received damages. For every valid claim filed, about six were filed over non-negligent care.⁷

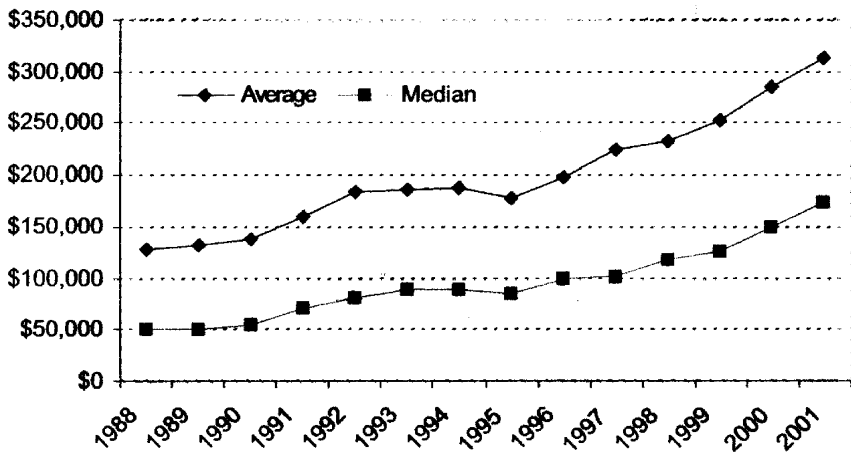


Fig. 3 Amount of money paid out to plaintiffs between 1988 and 2001.
 Source: From: Bovbjerg, R.R., and Bartow, A. (2003). *Understanding Pennsylvania's Medical Malpractice Crisis: Facts About Liability and Insurance, the Legal System, and Health Care in Pennsylvania*. Pew Project on Medical Liability.

There is no evidence that malpractice suits are a reliable indication of bad medical practice or inadequate providers. Litigation outcomes correlate more with the extent of the patient's injury rather than the fact of medical negligence. In comparing claims in obstetrics and nonobstetric cases, for example, Ross⁸ reports that obstetric anesthesiology claims contain a significantly higher proportion of what might be considered "minor" injuries, such as headache, back pain, pain during anesthesia, and emotional distress. The incidence of claims of "major events" (such as nerve damage, aspiration, death) was similar in the two groups of patients. The number and amount of paid claims are only weakly predictive of future litigation for any one individual professional.⁹ In any given year, 2% of the claims filed are responsible for about 50% of the damages paid to plaintiffs. Lawsuits are very costly to defend, averaging about \$23,000.¹⁰

I personally found this situation very alarming. In order to better understand the process and obtain insight into the medical negligence situation in greater detail, I decided to learn more about the legal system. It was a long haul, and I had major support from my family and colleagues over the four years going to law school took. It became clear to me that the best way a practitioner has to protect herself is to understand the risks of practicing her profession. This understanding would help her avoid as many risks as possible. Since I passed the bar in 1995, I have been teaching and lecturing genetic counseling professionals about risk management issues and techniques. One step in avoiding liability is to understand risk management. The present book is the result of my understanding of the legal system and the ways in which genetic counselors can negotiate the "potholes" in our day-to-day practices.

In the material that follows, the feminine pronoun is used in the manner of the practice of the legal literature. Some of the points raised may seem obvious, but they need to be said. Some issues may seem to be common sense, but they are not always taken as seriously as they should be. The content of this book has been prepared for educational and information purposes only. It is not to be considered or used as legal advice or a legal opinion on any specific matter. Any specific or personal questions you may have about your practice should be discussed with your attorney or risk manager.

Lessons Learned

Risk Management Issues in Genetic Counseling

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