

2002

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Recommended Citation

Robert J. Kane *Information Is the Key to Patient Empowerment*, 11 *Annals Health L.* 25 (2002).
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Information Is The Key to Patient Empowerment*

*Robert John Kane, J.D.***

I. INTRODUCTION

“Information is power” has been the mantra of the 1990’s and the new 21st century, and has even affected the health care delivery system. There is nothing new about this principle, especially with regard to health care. The practice of medicine was born, and has grown on the principles of obtaining knowledge and information about disease and the human condition to prevent and cure diseases and afflictions.¹ Most recently, this principle has required disclosure of information by all participants in the delivery of health care services, including, but not limited to, the patient, physician and managed care organization.

It is important to recognize that many powerful elements of our society impact or regulate the marketplace, as well as a patient’s ability to control his or her own destiny and make health care choices. Patients have a tremendous number of choices they may pursue: traditional forms of health care delivery such as medical, nursing or dental and alternative forms of health care services such as acupuncture, Chinese medicine, and naprapathy. To make the appropriate choices, patients need an understanding of their health history, including family history of diseases and conditions, as well as their own history of diseases and conditions. This knowledge also assists in making healthy lifestyle choices.

Today, most patients finance health care through some form of health insurance or managed care health benefit program,

* The thoughts, ideas, and positions expressed herein do not represent the policy of the Illinois State Medical Society and are solely those of the author.

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1. THEODORE R. LEBLANG ET AL, THE LAW OF MEDICAL PRACTICE IN ILLINOIS, § 1:2, 3-13 (2d. Ed. 1996 & Supp. 2001) [hereinafter LEBLANG].

generally referred to as “health benefit programs.” Typically, alternative forms of health care have not been covered under health benefit programs. However, in the 1990’s, health benefit programs have increasingly provided coverage for these alternative forms of health care services, citing the corporate desire to meet the needs of the people enrolled in, or insured by, the program.

Many changes have occurred in the health care delivery system which give patients more, and sometimes less control over health care choices and decisions. A truly empowered patient is one who has both the information and knowledge to take responsibility for the health care services necessary to maintain a healthy mind and body. This paper will discuss patient empowerment amid the many statutory, regulatory, professional and marketplace developments over the last decade. A checklist will set forth a number of questions for a patient to determine whether or not he or she has sufficient knowledge and information to take responsibility for his or her care and to make responsible health care decisions.

II. HEALTH CARE DELIVERY MARKETPLACE

Generally, the health care delivery marketplace has been evolving from one that was characterized by a physician delivering services to a patient with payment by the patient, to a complex system with many alternative forms.² Before World War II, medical services were typically provided by physicians on a fee for service basis. Over the years, the patient would develop trust in the physician and the necessary level of communication to allow the provision of high quality patient care. After World War II, health benefit programs provided insurance coverage and reimbursement to patients for health care services.³ Today, few fee for service health benefit programs exist. Rather, managed care has permeated most areas of the country to some degree.⁴ Managed care brought with it the promise of lowering, or

2. GERALD R. PETERS, *Healthcare Integration: A Legal Manual for Constructing Integrated Organizations*, NAT’L HEALTH LAWYERS ASS’N 14-18 (1995) [hereinafter PETERS].

3. SCOTT BECKER, *Health Care Law: A Practical Guide* § 19.02[2] (2d. ed. 2001) [hereinafter BECKER].

4. LEBLANG, *supra* note 1, at § 1:3, 13-17. See also Edward B. Hirshfield & Gail H. Thompson, *Symposium: on Physician Decision-Making and Managed Care: Medical Necessity Determinations: The Need for a New Legal Structure*, 6 HEALTH MATRIX 3, 6 (1996).

at least stabilizing, the cost of health care by limiting the patients' choice of health care professionals and the services that would be covered by the managed care health benefit plan.⁵ Generally, these limitations reduce costs because of volume discounts provided. Both of these forms of constraint directly affect the health care received or perceived to be received by patients because the patient and health care professional are not free to choose the best available course for care or treatment.

The major components of the health care delivery marketplace of today are the patients; the health care professionals and facilities; the payors, both governmental and private or third party; and businesses. All of these components are in a continuous state of change.⁶ In response to increased costs, expanded government regulation, the necessities of the marketplace and the demands of consumers and others, a variety of health care delivery systems have emerged.⁷ The health care delivery marketplace changes in the 1990's have been compared to the mergers and acquisitions in corporate America in the 1980's.⁸

Health benefit programs provide different forms of coverage for health care services provided to insureds or enrollees.⁹ These programs may or may not have restrictions on the physicians or hospitals that a patient can utilize. Health benefit programs are purchased by individuals, employers and governmental entities.¹⁰ Most programs are purchased or sponsored by employers with patients often paying for a portion of the cost of the program.¹¹ Originally, these systems did not restrict which health care professionals a patient could utilize or what a health care professional could do in terms of treatment.

However, with the advent of health maintenance organizations, preferred provider organizations and third party administrators, restrictions have been placed on both the health care professional and the patient.¹² These restrictions narrow which health care professionals that a patient is allowed to see for services, require a patient to choose a primary care physician to

5. PETERS, *supra* note 2, at 14-18; Douglas A. Hastings et al., *Fundamentals of Health Law*, NAT'L HEALTH LAWYERS ASS'N 245-261 (1995) [hereinafter Hastings].

6. See generally PETERS, *supra* note 2, at 14.

7. *Id.*; LEBLANG, *supra* note 1, at §§ 1:15 - 1:21.

8. BECKER, *supra* note 3.

9. Hastings, *supra* note 5, at 245-47.

10. LEBLANG, *supra* note 1, at § 1.21, 176.

11. LEBLANG, *supra* note 1, at § 1:17, 142-44.

12. Hastings, *supra* note 5, at 245-61.

coordinate all their health care services from a limited list, restrict the provider that may receive referrals from this primary care physician, require the health benefit program to approve the health care services that the physician believes necessary, and pressure physicians to follow health benefit program directives on how or by whom specific services are to be provided.¹³ The purpose of these restrictions or limitations is primarily to limit or stabilize health care service costs.¹⁴ Cost reductions are usually obtained through structural or operational integration.¹⁵ Thus, costs are controlled by controlling access and utilization. Government payors use many of the same techniques to limit the costs of the system.¹⁶

Business plays a significant role as a purchaser of health insurance or health benefit programs in defining the services covered and how the services are covered.¹⁷ Until recently, it would appear that in general, businesses simply negotiated for the most services for the least costs.¹⁸ In the process of searching for the best price, health programs are sometimes changed. In addition, health insurance and benefit programs would find new and usually restrictive ways to reduce costs. Often, this meant patients would have to change programs every year or two. Consequently, these patients may also have to change physicians. This cycle can lead to fragmented care and a deterioration of the traditional relationship between patient and physician. Recently, a number of businesses, such as the Leap Frog Group, which will be discussed in further detail in Section V, have taken a public stand to improve the quality of health care services through insisting on proven quality health care delivery mechanisms.¹⁹

13. LEBLANG, *supra* note 1, at § 1:17, 143-44.

14. LEBLANG, *supra* note 1, at § 1.21, 176-96.

15. PETERS, *supra* note 2, at 21-22.

16. Hastings, *supra* note 5, at 250-52.

17. THE LEAP FROG GROUP, *LeapFrog Purchasers*, at www.leapfroggroup.org/purchase.htm (last visited June 26, 2002).

18. See generally EMPLOYERS' MANAGED HEALTH CARE ASSOCIATION, *Partnering for Better Health - How Employers are Working with HMOs to Improve Quality* (1997); EMPLOYERS' MANAGED HEALTH CARE ASSOCIATION *Communicating Health Care Quality: How Pioneering Employers Keep Consumers Informed* (1997); THE LEAP FROG GROUP, *The Case for Leapfrog*, at www.leapfroggroup.org/about.htm (last visited Jun. 12, 2002) [hereinafter About LeapFrog].

19. About LeapFrog, *supra* note 18.

III. PROFESSIONAL STANDARDS RECOGNIZE THE NEED FOR ACTIVE PATIENT INVOLVEMENT THROUGH TAKING RESPONSIBILITY FOR HEALTH CARE DECISION MAKING

For decades, the prominent health care professional associations represented by the American Medical Association²⁰ and the American Hospital Association²¹ have recognized the patients' right to health care information. The American Medical Association policy specifically states that "A physician shall continue to study, apply and advance scientific knowledge, maintain a commitment to medical education, make relevant information available to patients, colleagues, and the public, obtain consultation, and use the talents of other health professionals when indicated."²² Likewise, the American Hospital Association policy specifically states:

The patient has the right to and is encouraged to obtain from physicians and other direct caregivers relevant, current, and understandable information concerning diagnosis, treatment, and prognosis. The patient has the right to review the records pertaining to his/her medical care and to have the information explained or interpreted as necessary, except when restricted by law.²³

In the mid 1990's, as patient rights were discussed in the marketplace and by state and federal legislatures, the professional associations adopted clear policies which reflect the reality that rights come with responsibilities.²⁴ Both physicians and hospitals essentially view patients' responsibilities as consisting of:

- Being truthful and expressing concerns clearly.
- Providing a complete medical history, to the extent possible, including information about past illness, medications, hospi-

20. AMERICAN MEDICAL ASSOCIATION, *Principles of Medical Ethics* (2001) [hereinafter AMERICAN MEDICAL ASSOCIATION]. For first Code of Ethics, see AMERICAN MEDICAL ASSOCIATION, *Original Code of Medical Ethics* (1847). See generally MORRIS FISHBEIN, *A History of the American Medical Association 1847 to 1947* (W. B. Saunders Co. 1947). See also AMERICAN OSTEOPATHIC ASSOCIATION, *Code of Ethics* (1998).

21. AMERICAN HOSPITAL ASSOCIATION, *A Patient's Bill of Rights* (1992) [hereinafter AMERICAN HOSPITAL ASSOCIATION]. See generally FISHBEIN, *supra* note 20.

22. AMERICAN MEDICAL ASSOCIATION, *supra* note 20, at § 5. See also AMERICAN OSTEOPATHIC ASSOCIATION, *Code of Ethics*, *supra* note 20.

23. AMERICAN HOSPITAL ASSOCIATION, *supra* note 21, at §§ 2, 7.

24. AMERICAN MEDICAL ASSOCIATION, Policy E-10.02 Patient Responsibilities (June 2001) [hereinafter AMA Policy E-10.02]; AMERICAN MEDICAL ASSOCIATION, *supra* note 20; AMERICAN HOSPITAL ASSOCIATION, *supra* note 21. See also AMERICAN MEDICAL ASSOCIATION Policy E-10.01 Fundamental Elements of the Patient-Physician Relationship (1993) [hereinafter AMA Policy E-10.01].

talizations, family history of illness and other matters relating to present health.

- Requesting information or clarification about their health status or treatment when they do not fully understand what has been described.
- Cooperation with the treatment plan and keep agreed upon appointments.
- Compliance with instructions to protect the public and themselves.²⁵

The professional duty of physicians and hospitals to provide health care information does not permit them to hand patients copies of articles or books because conveying information means more than simply handing out a book.²⁶ As seen in the development of medicine from a point where the physician made most of the health care decisions (paternalistic), to the modern health care delivery system where patients are involved in their health care and make decisions, effective communication must be provided.

The doctrine of informed consent provides a clear example of effective communication. As one commentator observed about informed consent: “The law is [sic] in almost every jurisdiction requires that a physician has the duty to disclose to his patient, prior to any treatment or procedure, sufficient information to enable the patient to make an informed decision.”²⁷

The informed consent doctrine developed over time out of the concepts of patient self determination, personal autonomy and reaction against unauthorized touching, or assault and battery.²⁸ Over time, the doctrine’s primary focus became not the unauthorized touching, but the extent of the information provided.²⁹ An informed consent cause of action became a lawsuit against a physician for negligent failure to provide adequate explanation of the type of procedure, alternatives and risks of the procedure.³⁰

Another example of effective communication is the physicians’ ethical duty to communicate with patients. This ethical

25. AMA Policy E-10.02, *supra* note 24; AMERICAN MEDICAL ASSOCIATION, *supra* note 20; AMERICAN HOSPITAL ASSOCIATION, *supra* note 21. See also AMA Policy E-10.01, *supra* note 24.

26. LEBLANG, *supra* note 1, at § 4:26.

27. BECKER, *supra* note 3.

28. LEBLANG, *supra* note 1, at § 4:27.

29. *Id.*

30. *Id.*

duty has taken many forms, including new legal duty concerning communication with deaf patients.³¹ The American's With Disabilities Act has been interpreted to require all health care professionals to provide effective communication for patients which could include the use of interpreters for deaf patients.³² These two examples demonstrate that providing information is not enough; the communication between health care professional and patient must be adequate and effective. Health care professional associations advise their members to encourage their patients to take responsibility for his or her own health care when they are physically and mentally able to do so.

IV. HIPAA PRIVACY RULES ESTABLISH A UNIVERSAL STANDARD FOR ACCESS TO, AND USE OF, PATIENT HEALTH CARE INFORMATION

The health care marketplace has been significantly impacted by the provisions of the Health Insurance Portability and Accountability Act ("HIPAA").³³ In 1996, HIPAA imposed many requirements on the health care delivery system.³⁴ Most notable for this discussion is the requirement that individually identifiable health care information must be kept private and confidential in accordance with universal privacy standards.³⁵ These standards set a precedent by calling for Congressional action to establish privacy standards. The failure of Congress to act prompted the required adoption of privacy rules by a federal agency.³⁶ Another precedent was the creation of a national universal privacy standard for health care information that

31. Americans With Disabilities Act of 1990, Pub. L. No. 101-336, Titles II and III, 104 Stat. 327 (codified as amended in scattered sections of 42 U.S.C.). *See also* ILL ATT'Y GEN, ACCESSING EFFECTIVE COMMUNICATION, (1995) *available at* www.ag.state.il.us/disabilities/communq&a.htm (last visited June 13, 2002).

32. *Id.*

33. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191 110 Stat. 1936 [hereinafter HIPAA].

34. *Id.* HIPAA established numerous requirements including barring health insurance or health benefit program limitations on pre-existing health care conditions in specified circumstances. The provisions, known as "Administrative Simplification," are noteworthy for this discussion. These provisions require establishment of the following: national standard health care provider identifier, national standard employer identifier, national standard health plan identifier, national individual identifier, national health care information, security and privacy standards, and national billing transaction standards.

35. 42 U.S.C. §§ 1320d-1320d(8). *See also* 45 C.F.R. pts. 160 and 164; 67 Fed. Reg. 14775 (March 27, 2002) for proposed changes.

36. HIPAA, *supra* note 33.

preempts all less stringent or conflicting state laws, rules and judicial decisions on the use and disclosure of health care information.³⁷

HIPAA privacy rules were established to serve the following purposes:

- To protect and enhance the rights of consumers by providing them access to their health information and controlling the inappropriate uses of that information.
- To improve the quality of health care in the U.S. by restoring trust in the healthcare system among consumers, healthcare professionals and the multitude of organizations and individuals committed to the delivery of care.
- To improve the efficiency and effectiveness of healthcare delivery by creating a national framework for health privacy protection that builds on efforts by states, health systems and individuals.³⁸

To meet these purposes, the Department of Health and Human Services (“DHHS”) adopted rules which regulate the use and disclosure of personal health care information referred to as “individually identifiable health information”³⁹ by regulated or covered entities.⁴⁰ The regulated or covered entities include any “health plan,”⁴¹ “health care clearinghouse,”⁴² and “health care provider who transmits any health information in electronic form in connection with a transaction covered by this subchapter.”⁴³ These rules, in part, require covered entities to do the following:

- Comply with rules requiring patient written consents and authorizations prior to use or disclosure of health care information.⁴⁴
- Permit patients to copy and inspect their own health care information.⁴⁵

37. 45 C.F.R. pts. 160 and 164. *See also* 67 Fed. Reg. 14775 (Mar. 27, 2002) for proposed changes.

38. *Id.*

39. 42 U.S.C. § 1320d(6); 45 C.F.R. § 164.501.

40. 45 C.F.R. pts. 160 and 164.

41. 42 U.S.C. § 1320d(1); 45 C.F.R. § 160.102.

42. *Id.*

43. *Id.* *See also* 45 C.F.R. § 160.103.

44. 45 C.F.R. §§ 164.502-514. *See also* 67 Fed. Reg. 14775 (Mar. 27, 2002) for proposed changes.

45. 45 C.F.R. §§ 164.502-524.

- Grant patients the opportunity to amend their health care information and to amend incomplete or erroneous information.⁴⁶
- Provide patients with an accounting of disclosures of their health care information for other than health care services, payment or operations.⁴⁷
- Provide patients with a statement of how their information is disclosed or used, referred to as a “Notice of Privacy Practices.”⁴⁸
- Grant patients an opportunity to restrict the use or disclosure of information.⁴⁹
- Grant patients the opportunity to file written complaints.⁵⁰

All of these policies create a universal standard for how health care information is used or disclosed. DHHS is continually modifying or changing these standards.⁵¹ After these standards become effective in April 2003, every patient in every state will be able to have direct access to their health care information. In addition, patients will be able to request an amendment to their personal medical record or health care information. While many states may allow such access and input, not all do. For instance, in Illinois a patient has direct access to their hospital records,⁵² but not to their health care professional records⁵³ with the exception of mental health records. Further, in Illinois the right to seek amendments to health care records is only provided with respect to mental health records.⁵⁴

Establishment of this universal standard of patient access to, and input in, health care information should facilitate patients’ ability to make health care decisions and take responsibility for the health care services received from various health care professionals and facilities. Patients will be able to obtain and amend current health care records, which should increase understanding and accuracy for records.

46. 45 C.F.R. § 162.524

47. 45 C.F.R. § 164.528.

48. 45 C.F.R. § 164.520(a).

49. 45 C.F.R. § 164.522(a).

50. 45 C.F.R. § 164.520(b)(vi).

51. 67 Fed. Reg. 14775 (Mar. 27, 2002).

52. 735 ILL. COMP. STAT. 5/8-2001 (2001).

53. 735 ILL. COMP. STAT. 5/8-2003 (2001).

54. 740 ILL. COMP. STAT. 110/4(c) (2001).

V. MARKET PLACE REGULATION: *To Err Is Human Report*

The Institute of Medicine's (IOM) infamous report "*To Err is Human: Building a Safer Health Care System*" (IOM Report) has sparked significant discussion as well as professional and institutional responses.⁵⁵ This IOM Report, irrespective of the statistics of projected deaths, served its purpose to awaken the health care industry to the need to reform itself to reduce health care errors.⁵⁶ The Report found that preventable health care errors were caused in part because of the fragmented nature of the health care delivery system.⁵⁷ This fragmentation takes the form of a multiplicity of health care professionals and facilities being involved in the services provided to a patient without access to complete information among these providers.⁵⁸ The Report's recommendations consisted of a comprehensive, four-tiered approach to reducing errors:⁵⁹

1. Establishing a national focus to create leadership, research, tools and protocols to enhance the knowledge base about safety.
2. Identifying and learning from errors through immediate and strong mandatory reporting efforts, as well as the encouragement of voluntary efforts, both with the aim of making sure the system continues to be made safer for patients.
3. Raising standards and expectations for improvements in safety through the actions of oversight organizations, group purchasers, and professional groups.
4. Creating safety systems inside health care organizations through the implementation of safe practices at the delivery level. This level is the ultimate target of all the recommendations.⁶⁰

Many of the recommendations depended upon the compilation or use of health care information to prevent errors.⁶¹ Health care information potentially would be used by a number of different entities to reduce or prevent errors, such as federal and state regulatory agencies, federal, state and private research

55. INST. OF MED., *TO ERR IS HUMAN: BUILDING A SAFER HEALTH CARE SYSTEM* (Linda T. Kohn, et al. eds., National Academy Press 1999) [hereinafter *TO ERR IS HUMAN*].

56. *Id.* at 3.

57. *Id.*

58. *Id.* See also PETERS, *supra* note 2, at 18.

59. *TO ERR IS HUMAN*, *supra* note 55, at 6-14.

60. *Id.* at 6.

61. *Id.* at 6-14.

organizations, health care professionals and health care providers.⁶² Many federal and state governmental entities are now in the process of attempting to determine how to respond to the IOM Report and institute measures to reduce health care errors.⁶³

A direct result of the IOM Report has been a keen awareness that patients are in a unique position to prevent errors when they are knowledgeable of their health care services. Many commentators have concluded that health care information in the hands of the patient can not only improve services, but also reduce the potential for errors.⁶⁴ In fact, federal entities have created documents similar to the patient empowerment checklist set forth below. The federal government's Quality Interagency Coordination Task Force developed "Five Steps to Safer Health Care" which basically calls for patients to retain and inquire about health care information.⁶⁵ These steps are as follows:

1. Speak up if you have questions or concerns.
2. Keep a list of all the medicines you take.
3. Make sure you get the results of any test or procedure.
4. Talk with your doctor and health care team about your opinions if you need hospital care
5. Make sure you understand what will happen if you undergo surgery.⁶⁶

Businesses can also help prevent errors. Business purchasers are the significant consumers, besides the government, of health care services.⁶⁷ Their purchasing of health care services for their employees allows them to have tremendous influence over the services provided. Business purchases are typically negotiated based upon the risks posed by the employee population and the costs of services with union agreements are a dominant

62. *Id.*

63. QUALITY INTERAGENCY COORDINATION TASK FORCE, *Five Steps to Safer Health* (2001) at www.ahrq.gov/consumer/5steps.htm [hereinafter TASK FORCE]; See also AGENCY FOR HEALTHCARE RESEARCH AND QUALITY, *20 Steps to Help Prevent Medical Errors* (2001) at www.ahrq.gov/consumer/20tips.htm [hereinafter AHRQ].

64. TASK FORCE, *supra* note 63; See also, AHRQ *supra* note 63; AGENCY FOR HEALTHCARE AND QUALITY, *Improving Health Care Quality: A Guide for Patients and Families*, (2000) at www.ahrq.gov/consumer/qutlite [hereinafter *Improving Health Care Quality*]; INSTITUTE FOR SAFE MEDICATION PRACTICES, *Information for the Patient* at www.ismp.org/Pages/Consumer.htm.

65. TASK FORCE, *supra* note 63; See also AHRQ, *supra* note 63.

66. *Id.*

67. Press Release, The Business Roundtable, Sponsored Initiative Focuses on Patient Safety (Jan. 26, 2000) available at <http://www.brtable.org/press.cfm/375>.

factor.⁶⁸ In the 1990's, businesses started aggressively negotiating not only on the basis of services, but on the quality of services as well.⁶⁹ The IOM Report recommended that employers get involved in creating incentives to reduce errors.⁷⁰ Specifically, the Report recommendation stated:

RECOMMENDATION 7.1 Performance standards and expectations for health care organizations should focus greater attention on patient safety.

- Regulators and accreditors should require health care organizations to implement meaningful patient safety programs with defined executive responsibility.
- Public and private purchasers should provide incentives to health organizations to demonstrate continuous improvement in patient safety.⁷¹

Business purchasers have since stepped forward by creating the Leapfrog Group which consists of Fortune 500 companies from around the country.⁷² The Leapfrog Group has adopted principles and goals to increase patient safety.⁷³ The group's mission is "to mobilize employer purchasing power to initiate breakthrough improvements in the safety of health care for Americans."⁷⁴ The group adopted goals which enhance quality of care and are easily assessed and feasible according to substantial evidence. The goals adopted are as follows:

- The mandatory use of computerized physician order entry in hospitals.
- The mandatory use of evidence based hospital referral systems.
- The mandatory use of critical care physicians in the care of hospitalized intensive care patients.⁷⁵

68. See generally Corporate Health Care Purchasing Among The Fortune 500, National Health Care Purchasing Institute (May 2001) (on file with the Annals of Health Law).

69. See generally EMPLOYERS' MANAGED HEALTH CARE ASSOCIATION, *Partnering for Better Health - How Employers are Working with HMOs to Improve Quality*, (1997); See also EMPLOYERS' MANAGED HEALTH CARE ASSOCIATION, *Communicating Health Care Quality: How Pioneering Employers Keep Consumers Informed* (1997); About LeapFrog, *supra* note 18.

70. TO ERR IS HUMAN, *supra* note 55, at 10-13.

71. *Id.* at 11.

72. About Leapfrog, *supra* note 18.

73. *Id.*

74. *Id.*

75. *Id.*

VI. PATIENT EMPOWERMENT

Patient empowerment means many things to different people depending upon their involvement in the health care field. For the purposes of this discussion, “patient empowerment” means giving patients the ability or authority to direct and be responsible for their health care services by providing them information. Patients generally have taken varying degrees of responsibility for their health care services. Historically, patients could not have retained copies of healthcare information because any questions could be answered by their healthcare professional or provider. The patient’s healthcare professional would routinely inquire as to the patient’s compliance with instructions or in a small community could be able to informally monitor compliance. Today, patients may go to the same office, but not always see the same healthcare professional. Further, patients often need tests, evaluations, or procedures that cannot be provided by the same health care professional or health care provider.

Patients typically may be involved with multiple health care professionals and facilities to address a particular illness, condition or complaint. The need to coordinate all of these services gave birth to the managed care position of “gatekeeper” or primary care physician.⁷⁶ The gatekeeper coordinates the services provided by the various health care professionals and providers, assimilates the test and procedure information and informs the patient of significant results and conclusions.⁷⁷ While this system assists in reducing problems associated with the fragmented delivery of care, difficulties still exist. The gatekeeper does not always receive the necessary information from the other health care professionals and providers, the health care professionals and providers may order additional tests, procedures or medication of which the gatekeeper is not informed. The more significant set of problems exist when patients seek services from a variety of health care professionals and providers on their own and do not inform the gatekeeper or other physician to coordinate services.⁷⁸

The fragmentation of the health care delivery system demands that patients take control and know their own history. Patients are the best participants in the health care delivery sys-

76. Hirshfield & Thompson, *supra* note 4, at 31. See generally THE MANAGED HEALTH CARE HANDBOOK (Peter Kongstvedt ed., 2d ed. 1993).

77. Hastings, *supra* note 5, at 246.

78. See generally TO ERR IS HUMAN, *supra* note 55.

tem to truly know and be responsible for their overall care and treatment that they receive.

Professional provider standards support patients not only receiving health care information, but making health care decisions.⁷⁹ In fact, the physician-patient relationship is the most important aspect of providing health care services.⁸⁰ A fundamental element of this relationship is the sharing of information:

From ancient times, physicians have recognized that the health and well-being of patients depends upon a collaborative effort between physician and patient. Patients share with physicians the responsibility for their own health care. The patient-physician relationship is of greatest benefit to patients when they bring medical problems to the attention of their physicians in a timely fashion, provide information about their medical condition to the best of their ability, and work with their physicians in a mutually respectful alliance.⁸¹

This relationship is a collaboration or team alliance where the persons work together. Patients who know their health history and take responsibility for their health care services receive the greatest benefit from that care.

Additionally, the principle hospital accreditation body, the Joint Commission on Accreditation of Healthcare Organizations, just recently adopted new patient safety standards encouraging hospitals to share more information about treatment with patients including health care errors.⁸² Consequently, new efforts are being made to facilitate hospitals sharing more information with patients around the country.⁸³

Furthermore, in recognition of a growing awareness that patients need to know more and in recognition of “[g]overnment agencies, purchasers of group health care, and health care providers are working together to make the U.S. health care system safer for patients and the public,” the Agency for Healthcare

79. Patient’s rights to information and responsibilities to use are set in the following: AMA Policy E-10.02, *supra* note 24; AMERICAN HOSPITAL ASSOCIATION, *supra* note 21; AMERICAN MEDICAL ASSOCIATION, *supra* note 20. See also Policy E-10.01, *supra* note 24.

80. BECKER, *supra* note 3. See generally LEBLANG, *supra* note 1, at § 4:4, 677-680; Becker, *supra* note 28.

81. AMA Policy E-10.01, *supra* note 24.

82. JOINT COMM’N ON ACCREDITATION OF HEALTHCARE ORG. Revisions to Joint Commission’s Standards in Support of Patient Safety and Medical/Health Care Error Reduction, RI 1.22 and Intent of PF.3.7 (July 1, 2001) at http://www.jcaho.org/standard/fr_ptsafety.htm.

83. *Id.*

Research and Quality created a patient safety fact sheet.⁸⁴ This public document entitled “20 Tips to Help Prevent Medical Errors”⁸⁵ sets forth twenty things patients can do to not only reduce errors, but take responsibility for their health care services. These tips stress “[t]he single most important way you can help to prevent errors is to be an active member of your health care team,” then sets forth specific tips under the categories, “medicines,” “hospital stays,” “surgery” and “other steps you can take.”⁸⁶

Legal barriers to patients’ access to health care information have been significantly reduced with the recognition of a physician’s duty to provide informed consent,⁸⁷ the patients’ rights to make advance directives and the professional or provider’s duty to document directives in the individual’s medical record,⁸⁸ and patients’ right to health care information.⁸⁹ These barriers either prevented a patient from obtaining his or her records or making health care decisions.⁹⁰

Some marketplace forces currently encourage patients to control health care decision making and to reduce costs. Health benefit programs impose significant limitations on patient choice. A reality of the marketplace is that patients are not allowed to receive anything they want regardless of cost. Except as limited by health benefit programs, patients have the right to decide what health care services they will receive even with these limitations. Additionally, patients may still receive necessary services through private payment. Now patients must accept responsibility for making decisions to continue to improve the quality of health care services and to protect themselves from errors.

VII. PATIENT EMPOWERMENT CHECKLIST

Many patients need assistance in knowing what questions to ask in order to better understand their health care services.

84. AHRQ, *supra* note 63.

85. *Id.*

86. *Id.*; See also TASK FORCE, *supra* note 63.

87. See also Clarence H. Braddock et al., *Informed Decision Making in Outpatient Practice: Time to Get Back to Basics*, 282 J. AM. MED. ASS’N 2313 (1999).

88. 42 U.S.C. § 1395cc(f)(1)(B) (requiring all federally funded health care facilities and others to provide patients with written information about their rights to make health care decisions including advance directives). See also LEBLANG, *supra* note 1, at § 8:20.

89. 45 C.F.R. 164.524 (2002) (HIPAA Privacy Rules).

90. See generally BECKER, *supra* note 3.

These questions are simply a way to understand the whole health care situation. This section includes examples of helpful suggestions for a patient to determine whether or not he or she has sufficient knowledge and information to take responsibility for his or her care and to make responsible health care decisions.

*1. Do You Have a List of All Your Illnesses or Conditions For Which You Sought Health Care Services, Including Any Therapies, Treatments or Medications Received?*⁹¹

Patients should develop a concise and comprehensive list of all illnesses and conditions for which they have sought care. This is similar to a history and physical completed by a health care professional. It should be compiled contemporaneously with the services that are documented to avoid mistake or confusion. At a minimum, the following information should be included:

- Date of birth, ethnic background
- Allergies to medicines, foods, fluid, etc.
- Chronic illnesses and treatments
- Surgeries and major illnesses (if female, obstetric history)
- Immunization record
- Current medications (including over the counter or alternatives such as herbs and roots)
- Family history of major or chronic illness including cancer, diabetes, high blood pressure and cardiac problems

Patients with such a list will be better prepared to discuss their health care service needs than those patients who rely solely upon memory. This information is the fundamental information that the health care professional needs to help assess the patient's illness and condition. A significant problem with this recommendation is the historic inability of patients to remember exactly what health problems they have had and the care and treatment that was provided. Contemporaneous creation of this list should reduce the possibility of errors. Patients can of course also double check their summary of the services with the health care professional.

91. AHRQ, *supra* note 63; TASK FORCE, *supra* note 63.

2. *Do You Check On Your Health Care Professionals' Education and Experience or Your Health Care Facilities' Experience?*⁹²

Patients should investigate the health care professional or facility from which they are, or will, be receiving services. Patients should know the background and experience of their health care professionals in the service the patient is seeking. Health care is both an art and a science. Numbers and statistics cannot truly capture the extent of a health care professional's experience. The best sources of information about a health care professional are the physician or health care professional who refers the patient for services, friends, family and former patients. Some resources exist to gather information about a physician, including state licensing agencies, the Federation of State licensing agencies and American Medical Association Physician Profiles.

Advocates for mandatory access to professional liability information argue that it is significantly important and should be disclosed in an easily accessible format. However, there are numerous reasons why a lawsuit is settled besides poor health care, such as the lack of documentation of the service provided or business decisions of the professional liability insurance company. Each of these reasons, however, can be wholly unrelated to the quality of care and the public disclosure of professional liability information is unduly prejudicial. For instance, non-documented services may have in fact been provided and evidence other than the documentation, such as laboratory results and prescriptions, may exist to show that the services were provided; documentation may have nothing to do with the quality of services. In fact, the prejudicial nature of this information is the reason that the systems that require public disclosure do not include actual figures and do include descriptive information.

A significant impediment to the investigation of health care deliverer's background exists in emergency or emergent situations where obtaining information is difficult or impossible. Another problem could arise if a patient substantially delays necessary treatment because of an exhaustive search of the health care professional's experience. Anecdotally, some patients have been known to delay treatment while waiting for the right doctor or hospital to go to that their disease progresses to the point where no treatment will help cure them.

92. AHRQ, *supra* note 63; TASK FORCE, *supra* note 63.

3. *Do You Have a List Of All Your Current Prescriptions, Over The Counter Medications and Assistive Devices?*⁹³

A potential problem is that the physician and/or pharmacist may not know the alternative medicines being taken. This lack of information could lead to an adverse reaction by the patient to care or treatment provided by the physician- if the physician knew the specifics of the herbs the physician may have been able to prevent or avert the adverse reaction. Patients should therefore maintain a list of all current prescriptions and over the counter medications, including alternative medicines and herbs. This list should at a minimum include (1) the name of the medications or medicine; (2) dosage; (3) when it is taken; (4) when it was started and (5) the reason(s) for taking the substance. This list should be provided to the patient's health care professional, especially any physician and pharmacist. Patients should specifically inquire of their health care professional whether there are any concerns or risks with taking these substances at the same time. Patients should also include over-the-counter medications taken as needed such as Tylenol in case of a headache or Sudafed for a cold.

4. *Do You Inform Your Health Care Professionals and Health Care Facilities of The Treatments You Are Receiving at The Time You Seek Services?*⁹⁴

Patients should inform the health care professionals and health care facilities of the treatments or services that the patient is receiving from other health care professionals or facilities. This information is vital to the assessment of necessary services, but also to avoid potential conflicts between the services received from different sources. Patients typically will not know the counter indications or conflicts between services and must provide their health care professional or facility with the information necessary to avoid these problems.

A potential problem is the loss of privacy for the patient. Not all patients are willing to share their health information even with their health care professional. However, this disclosure is essential to avoid conflicts and poor health care. Health care professionals cannot properly treat patients with out accurate and complete information from the patient.

93. AHRQ, *supra* note 63; TASK FORCE, *supra* note 63.

94. *Id.*

5. *Do You Ask Questions When You do not Understand Something or Something Confuses You?*⁹⁵

Patients should take the initiative and inquire of their health care professionals or facilities why they are receiving services, what the expected outcome should be and what complications or problems should be watched for in the delivery of health care services. A knowledgeable patient willing to ask “WHY” can prevent health care errors from occurring. Further, the fragmented nature of the health care delivery system allows for multiple points at which simple human error can occur and harm a patient. Patients simply need to keep asking questions until they believe they understand.

6. *Do You Insist Upon Legible Instructions From Your Health Care Professional or Facility?*⁹⁶

Patients will be more informed as to the need for therapies, treatments or medications with written instructions. This information will be available for referral at a later date. Taking charge of coordinating your care necessitates this information, since contemporaneous and subsequent treating health care professionals need complete and accurate information. If a patient needs large print, has learning disabilities or cannot read, he needs to inform his health care professionals.

7. *Do You Know Which Health Care Services are Covered and Which Health Care Professionals or Facilities are Authorized by Your Health Benefit Program?*

Patient’s with health benefit programs should review all the coverage materials they receive. If patients have specific health care conditions or concerns, they should inquire about the program’s coverage before accepting or choosing the program. Patients with specific diseases may want to contact disease specific organizations such as the American Cancer Society for their comments or recommendations.

Generally, the patient responsibility statements of the American Medical Association and the American Hospital Association can also be reviewed.⁹⁷ These statements express patient responsibilities as follows:

95. *Id.*

96. AHRQ, *supra* note 63; TASK FORCE, *supra* note 63.

97. AMA Policy E-10.02, *supra* note 24; American Hospital Association, *supra* note 21. See also AMA Policy E-10.01, *supra* note 24.

- Being truthful and expressing concerns clearly.
- Providing a complete medical history, to the extent possible, including information about past illness, medications, hospitalizations, family history of illness, and other matters relating to present health.
- Requesting information or clarification about their health status or treatment when they do not fully understand what has been described.
- Cooperation with the treatment plan and keep agreed upon appointments.
- Compliance with instructions to protect the public and themselves.⁹⁸

In addition to the checklist given above to help empower patients to be responsible for their care, some patients may want to keep copies of their health care records. If so, patients should compile copies of their health care records in an organized fashion. These records can be organized in any number of ways such as chronologically or by illness or condition. The materials should clearly indicate the name, address, and telephone numbers of the health care professionals and facilities which provided health care services.

VIII. CONCLUSION

Patients are in a unique position to take charge of, and responsibility for, all of the care they receive from a variety of sources. Patients seek the care in the first place. Information is the key to patients taking charge of their health care, and only patients know if they take their medications. These patients have few legal, or governmental barriers to hinder them from being responsible for their own care. Patients coming forward to take control of health care decision making can lead to better quality of care and better health.

Over the last decade, the continuing changes in the health care delivery system have revealed the obvious truth that there is a difference between access to information and use of the information. Patients should take this opportunity to use their health care information and become partners with their health care professionals in the delivery of health care services.

98. *Id.*