

# Patient Advocacy for Health Care Quality

Strategies for Achieving Patient-Centered Care

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*We cannot seek or attain health, wealth, learning, justice or kindness in general. Action is always specific, concrete, individualized, unique.*

—*John Dewey*

To Scott Pearson, whose untimely death inspired this work, and to Tom Ferguson, whose optimism and energy propelled us forward.



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## FOREWORD

Much of my career has been spent considering what makes a good and safe healthcare environment, from my days as a local public health officer to my role today leading a top academic healthcare system.

In 1986, when I served as administrator of the Health Care Financing Administration, we published the first mortality information on Medicare beneficiaries at the nation's hospitals. The importance and role of quality in health and healthcare outcomes were relatively new ideas at the time. Despite the sophisticated statistical approaches we used and the efforts we made to include a range of experts in the process, the report's release was controversial. As I look back on that project, the mortality rates themselves were the least important aspect of that effort, although they were the focus of the most discussion. At the time, we did not have common agreement on what quality in healthcare meant, and the idea of measuring and changing was a pretty radical notion. Nonetheless, the concept of measuring, changing, and expecting quality was compelling, and in 1988, we launched the Health Care Financing Administration Effectiveness Initiative, premised on the idea that quality of care should be a unifying concept in all of healthcare.

Over the next 10 years, a number of distinguished scientists, policy makers, and healthcare advocates worked through panels, individual research, and well-known reports to add greatly to our understanding of healthcare quality. Ultimately, the Institute of Medicine defined it as "the degree to which health services for individuals and populations increases the likelihood of desired health outcomes and are consistent with current professional knowledge." Later, the Institute of Medicine added the ideas that high-quality care should be patient-centered, timely, efficient, effective, safe, and equitable. It should also be coordinated, compassionate, and innovative.

Overlaying each of these elements of quality care is the basic premise that they are achieved through systemic change and commitment to care. Quality improvement, whether focused on decreasing medication errors or increasing sensitivity to patients' cultural needs, only happens when systems are in place to support the good efforts of individuals within the system. In the landmark Institute of Medicine report *To Err Is Human*, a strong case was made that the best way to reduce medical

errors was to focus on systemic failures, not individual human ones. Indeed, I contend that failure on *any* of the quality of care constructs is generally attributable to system-wide weaknesses. That fact substantially increases the potential impact of advocacy on healthcare and health outcomes—applying pressure on the healthcare system can affect the behaviors of many individual caregivers simultaneously by changing the systems that support their work.

This important book focuses on the key question—where does patient advocacy fit? What role does it play in changing the healthcare quality landscape? In 2003, more than 60 leaders from a number of disciplines met at a critical patient advocacy summit in Chapel Hill, North Carolina. At that time, Dr. Carolyn Clancy, director of the Agency for Healthcare Research and Quality, asked what I thought was the right question: “Do we need an ‘army’ of good advocates, or do we need a better system in which advocates are not necessary?” The answer was and is simply “yes”—we need both. Changing the quality of our healthcare and ensuring that it is appropriate and safe will demand that individuals advocate for themselves and others on the basis of each of the elements of quality listed previously here. But as the system changes, each new healthcare iteration also means that advocates will need to adapt their approach if they are to continue playing a significant role in quality improvement in the foreseeable future.

The authors of the IOM’s *Crossing the Quality Chasm* described an approach to change based on the idea of evidence-based, patient-centered, and systems-minded care. Advocacy can and should have an important role in each element of this approach—in gathering and interpreting data and ensuring that care is based on good science, in ensuring that the patient and the patient’s needs and wishes are at the center of every healthcare decision, and in insisting that the care delivered be cooperative and coordinated across disciplines and organizations. Authors of the *Quality Chasm* went further to endorse 10 simple rules as a framework for high quality care, each of which describes a touch point for advocates and the advocacy process. These rules are not easy to implement, but they are straightforward and compelling in this simplicity.

For example, although the old model of care was focused on healthcare visits, the new model embraces the idea of a continuous healing relationship. Yet to attain this ideal, we need the constant advocacy of patients, their families, and the clinicians who care for them. In turn, a system based on continuous healing relationships will be one in which patients’

needs are more easily and naturally communicated so that the system itself advocates for patient-centered care.

In another of the 10 simple rules, providers whose decision making was primarily based on training and experience should now also base their decisions on evidence. Evidence-based care is or should be consistent across individual clinicians. The scientific basis for many healthcare approaches is increasingly available to patients and their advocates, for example, at [www.ahrq.gov](http://www.ahrq.gov), and can be a powerful tool in the advocacy process.

As a final example, in the old system of care, secrecy (e.g., about error rates) is necessary, but if the 10 simple rules are followed, transparency is essential. Transparency means that patients and their families can easily obtain the information they need to make good healthcare decisions and to advocate for the care they need from providers and health systems. The trend toward transparent care began with the publication of Medicare mortality information in the mid 1980s and continues, for example, with data on hospital care published by the Department of Health and Human Services at [www.hospitalcompare.hhs.gov](http://www.hospitalcompare.hhs.gov). Organizations such as the Institute for Healthcare Improvement, as well as patients and their families, have made advocating for greater transparency with patients when and if errors do take place a priority.

Unfortunately, the backdrop for this trend is one in which the gap between the best possible care and the care routinely given remains large, and studies bear out that the consumer's widespread demand for quality healthcare is not yet a reality. Six years ago, in *To Err Is Human*, the Institute of Medicine reported that tens of thousands of deaths each year are directly attributable to medical errors that occur in hospitals alone. Recently, the Institute's *Preventing Medication Errors* report stated, among other significant findings, that medication errors harm at least 1.5 million people and cost \$3.5 billion in additional costs in the inpatient setting annually. The report finds that adverse drug events are common, costly, and preventable. Eliminating them requires a change in the patient-provider relationship, a greater reliance on information technologies and electronic prescribing, proper training to make sure that new technologies are well-integrated into the system and are not just an add-on, and improved labeling and packaging of medications.

I believe that a critical role for advocates today and in the near future will be in supporting the use of electronic resources in medical decision

making. Physicians, patients, and their families should have access to every bit of information they need to make good healthcare decisions. They should understand the costs involved, their options, and their risks. Doctors and nurses should have at their fingertips information on best practices and standards of care and feel confident that the system in which they operate fully supports them. Through the adoption of clinical information systems, outcomes data collection, and the use of electronic medical records, we are taking incremental steps to ensure that healthcare quality measurement, reporting, and decision-making will yield more valid and reliable results. Standardization is important in driving safety and reducing errors, whereas more efficient seamless systems will dramatically encourage adoption of electronic medical records and other cost-saving technologies.

Developing a system of care based on state-of-the-art electronic resources requires that forward-thinking individuals advocate for it, that individuals and groups use the system to advocate for better care, and that the system itself be continuously improved through the efforts of individuals advocating for even better science.

Patient advocacy, in essence, is a central driver of all aspects of quality improvement. As this timely and comprehensive book demonstrates, patient advocacy—in its many forms—is a powerful source of pressure to initiate and follow through on the needed changes in our healthcare system. As we see in this volume, patient advocacy may occur with individuals advocating on behalf of individual patients, or it may take a broader organizational form. Regardless, an essential tenet is the encouragement—even the insistence—of the partnership in which patients participate with the healthcare system to affect their outcomes.

We may very well see patient advocacy taking root as an academic discipline as its importance becomes better understood. I have strongly supported the idea of a university-based center for consumer health advocacy that could be a powerful mechanism for gathering information, conducting research, evaluating advocacy approaches, and disseminating key findings. Whatever the direction patient advocacy takes, this important book will set the stage, providing a starting point, a taxonomy, and a common language for understanding, studying, encouraging, and developing advocacy in healthcare.

Our healthcare system is in need of change. Advocacy will be an important lever to affect key touch points in the system that will in turn support

patient care that adheres to the quality tenets we all value. As the system supports advocacy, advocates will support an improving system. Advocating for better healthcare is not an optimal choice—I believe it is our imperative.

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## **PREFACE**

### **The Public Health and Medical Continuum**

The common denominator shared by public health, with its focus on prevention, and medical care, with its focus on cure, is the end user—the individual viewed as patient, client, customer, or consumer. Public health and medical care have been linked sporadically, but they are more often regarded as distinct and separate fields—prevention versus cure—rather than as equal and complementary partners in the health care system of the United States. The citizen is supported by the many public health facilities and services offered at local, state, and federal levels. When that citizen becomes ill, the medical care system—private physician, public clinic, or hospital—takes over. Yet rather than looking at these modalities as separate entities, this book examines major points of intersection between public health and medical systems. In analyzing what happens to patients, from entry into the healthcare system until their ultimate outcome, this book focuses on public health tools that can help ameliorate the problems many citizens face when they become ill.

What mechanisms are available to ensure citizens that the links in the chain of public health and medical care—the two most important system components—are not broken? Patient advocacy is the navigator, both in its aim to help and guide patients to make well-informed decisions about their health for the best outcomes, and in its quest to create more effective systems and policies.

### **The Role of Personal Experience**

As in many health and social movements in the United States, the authors of this preface became increasingly aware of the need for patient advocates through personal experiences. After helping two close family members through life-threatening illnesses, Clarence realized that there was great need, but not formal and consistent recourse, for effecting positive change in the lives of patients everywhere. His first wife, June, died in 1967, when their son was a toddler. Then, in 2001, his son Scott died of malignant melanoma at age 38.

During Scott's battle with cancer, Clarence and Laurie Norris, Scott's stepmother, witnessed Scott's frustration with a treatment regimen orchestrated by multiple providers, with little acknowledgment of Scott or his family as decision-makers or partners in care; neither Scott nor his family were given options for participation as full and informed partners in healthcare decision-making. They saw a system in disarray, with doctors not communicating, hospital records not being shared among various institutions providing Scott's care, and patients often treated with little respect or dignity.

Critically ill patients often must serve as their own advocates. They often must react to multiple healthcare providers, research their own illnesses, and negotiate with insurance providers even as they face financial strain, negotiate for reduced work time, and cope with the stress of illness. Scott Pearson's case was hardly an exception. During the course of his care, Scott was moved seven times among five institutions. His hospital bills, representing seven months of care in the five institutions, listed 49 physicians as healthcare providers. Although Clarence visited his son every day throughout that time, he met only five physicians. From the day Scott was referred by his family physician to a hospital, neither Scott nor his father heard from this physician again.

The night the hospital called to tell his family that Scott had died, Laurie and Clarence discussed with Dr. Alison Norris (Laurie's sister) about what action the family could take as a memorial to Scott and his struggle. Dr. Norris, an intensivist, nephrologist, and long-term patient advocate in her own practice, served as Scott's patient advocate, helping the family understand in plain terms what was happening and what kind of information his providers should have shared with them to facilitate patient and family decision-making. Yet much of this communication with Scott's providers was characterized by a struggle to elicit information. More often than not, Dr. Norris experienced a lack of cooperation or resistance as she tried to advocate for Scott with her peers. The family recognized that theirs was not an isolated case. If Scott had experienced so many barriers to excellent care, even with the advocacy of an attentive family and a highly trained physician, others must be suffering even more. After the family discussed various options, Alison suggested a fund to support what would have made a difference for Scott's care; patient advocacy practiced effectively in an environment supporting such actions and with full participation of all the actors in a patient's case.

Clarence Pearson and Laurie Norris whole-heartedly agreed and, soon thereafter, established a fund in memory of their relatives to advance the



aims of patient advocacy at the University of North Carolina School of Public Health at Chapel Hill. The Scott and June Pearson Fund for Patient Advocacy has allowed the school to research patient advocacy, develop this textbook and curriculum, disseminate findings to all stakeholders, and develop research-driven, theory-based strategies that can improve conditions for patients and their families.

In our vision, patient advocacy empowers patients and their families as partners in their own healthcare by fostering interactive communication with the patient's team of healthcare providers and by offering resources for well-informed decision-making. The patient advocate helps ease a patient's "administrative" burdens by taking such steps as: making sure providers talk to each other, getting the go-ahead for procedures, finding out what insurance policies cover, or extending a hospital stay. Moreover, as explored in this book, the roles advocates play can extend beyond one-on-one efforts and across professional disciplines so that they develop materials, websites, and organizations for patients, restructure systems to make them safer, and lobby for policies that ensure people's access to care. Many people can serve as patient advocates—family members, doctors, nurses, and insurance providers as well as patients themselves.

There are still many things to learn about the basic problems patient advocates attempt to solve. For example, how do cultural, gender, and literacy differences change the way patients and providers share and understand information? How do these differences affect what questions get asked, how questions are framed, and the kind of answers given? By posing such questions, and by delineating what we already know, this book marks an important goal in the search for viable answers.

### **Public Health Education: The Roots of Patient Advocacy**

The term "patient advocacy" is of recent use but has its roots in the much broader field of public health education that became a social force beginning in the early 1900s. Clarence Pearson, as a public health educator, was well acquainted with the early history of advocacy for health, having worked at MetLife, a leading insurance company, for much of his career. Early in the nineteenth century, the private sector—principally the insurance industry—established the first organized, private-sector, public health education program. Metropolitan Life took the lead in this area by establishing a very early example of an advocacy program directed to a specific audience—

“industrial policyholders.” The working class policyholders of the time—the year was 1909—represented many nationalities, reflecting the large influx of immigrants into the U.S. in that era. In many cases, these immigrant populations were poor, had minimal access to health care, and had little exposure to modern educational movements for what MetLife called “the preservation of health and the conservation of life.”

MetLife clearly had a stake in making sure their policyholders remained healthy and had increased longevity. At the same time, however, MetLife felt that in dealing with these members of the industrial classes, it had an obligation beyond that contained in the policy contract. They put this commitment into action by designing an innovative, extensive, and socially useful program.

Visiting the homes of industrial policyholders weekly to collect small premium payments—as little as 10 cents per payment—MetLife’s agents were as familiar as the milkman and the mailman. Agents distributed company publications on health, hygiene, and safety. They became pioneers and early advocates for patient health, sharing with their clients *The Metropolitan*, a quarterly magazine published by MetLife written in popular style on subjects dealing with the health of the family, and particularly with the health of children. Each edition was printed in eight languages. One of the many pamphlets published by MetLife in 1913, “All About Milk,” was authored by Professor Milton J. Rosenau, Professor of Preventive Medicine at Harvard University and later the first Dean of the School of Public Health at the University of North Carolina at Chapel Hill.

As an advocate for good health, MetLife realized early on that literature in itself was insufficient for the complete development of its campaign of advocacy for education and prevention. Recognizing the effective role of nurses, both in assuring some continuity of care and in serving as key advocates for the patient, in June 1909 MetLife organized the Visiting Nurse Service. Through this program, nurses visited the homes of sick industrial policyholders to provide onsite services. The visiting nurses, as advocates of the patient through their work, provided the personal contact that connected the policyholder, the insurance company, and the healthcare system.

To “get the word out” about this innovative program, MetLife agents distributed circulars explaining details of the service, emphasizing that it was without cost to policyholders and that visiting nurses would work under the guidance of the physician in charge. Agents provided each policyholder with a mailing card addressed to MetLife’s local office. The card was filled out and mailed by the policyholder in case of need, and the visiting nurse

called at the earliest possible time. But insurance agents, continuing in their advocacy role, reported a large number of cases directly over the telephone when they encountered ill clients during their weekly rounds.

Visits were primarily requested for acute diseases and conditions where there was a strong possibility of recovery. In those days, illnesses under this heading included pneumonia, influenza, bronchitis, and various children's ailments. MetLife also provided maternity service after the mother had been insured for one year.

Under the rules of the service, a nurse was not permitted to make more than one visit without a physician in attendance. Where patients were too poor to engage a physician, the nurse frequently took on the duty of securing the voluntary service of some physician he or she knew or requesting the attendance of the city or county physician. The nurse helped the patient through the healthcare system of that time—an early example of patient advocacy. The service of visiting nurses introduced by MetLife also influenced the establishment of Visiting Nurse Services, Inc., a national nonprofit organization.

The MetLife visiting nurse service ended in the 1950s; its health and safety education division activities continued into the 1990s. Myriad letters of appreciation sent to MetLife from patients, nurses, and physicians testified to the invaluable work of the visiting nurse; without this home care, many patients would not have been restored to health or even have survived. MetLife's service supported the concept attributed to many great business organizations, "Doing Good While Doing Well." The MetLife Foundation carried on health and safety education activities after the Health and Safety Education Division of MetLife was dissolved.

### **Patient Education and Advocacy in Medical Care Settings**

In the early 1960s, only a handful of the existing 7,500 hospitals in the U.S. had organized patient education programs—another important component of patient advocacy. Yet as hospitals and clinics began to evince a growing interest in capitalizing on "teachable moments" to educate both inpatients and outpatients, MetLife's Health and Safety Education Division responded by providing a grant to the American Hospital Association. These funds allowed experts in the field to convene to establish guidelines for hospital-based patient and community health education programs sponsored and implemented by hospitals.

## **Patient Advocacy and Medical Care Delivery in Changing Times: Some Thoughts for Moving Ahead**

The “family physician” was once a cornerstone of person-centered care over the course of a patient’s life. The physician delivered babies, treated sickness, visited or called the patient daily during an illness, admitted the patient to a hospital and followed the patient during hospital treatment through recovery at home, helped the patient find a nursing home or after-care facility if needed, and would most likely be in attendance at the patient’s eventual funeral service. Yet this “personal touch” between patient and provider—the continuity of care so important to the generation of the 1930s, 1940s, and 1950s—has been overshadowed in the last 50 years by the reliance on new technologies and specialists, the need to contain rising healthcare costs, and the emergence of more complex health systems. These dramatic changes in the healthcare environment have meant that few physicians are able to carry out the multiple roles they once embraced. Unfortunately, as the authors of this preface have themselves experienced, the gap created by this change in physician roles has yet to be filled.

What measures must we take to make the healthcare industry accountable to the patient—as both customer and client? One answer is patient advocacy, which has the patient’s interests as a priority. The father of American management, Peter Drucker, suggested the first action of leadership. An industry, in this case health care, should ask itself, “What is our mission? Who is our customer? What does the customer value? What are our results? What is our plan?” Peter Drucker also offered this guidance, “You determine your primary customer—the person whose life is changed because of your work.”

This book represents leadership and innovative thinking in the field of patient advocacy. The values, practices, and points of view represented here can further the dialogue on healthcare reform. These chapters contain stimuli for all participants in the system—ranging from patients to providers to policymakers—to take action for progressive change.

Alison Norris, MD  
Laurie Norris, MA  
Clarence Pearson, MPH

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In the four years since we began planning the first patient advocacy conference at the University of North Carolina at Chapel Hill through to the editing and publication of this volume, we have been repeatedly—and forcibly—reminded of the urgent need for patient advocacy and patient-centered responses to the healthcare crisis we face today. The efforts of more than one hundred patient advocacy conference participants in 2003 and 2005, the many patient advocacy education and research programs around the country, as well as the insights of sixteen Carolina students and twenty guest speakers in our first patient advocacy course all attest to the vigor of this emerging field and demonstrate its significance to the quality of people's lives.

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