Introduction
CHAPTER 1

What Is Patient Advocacy?

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OBJECTIVES

• To introduce traditions of advocacy, including those related to nursing, palliative care, and breast cancer activism
• To show the importance of the patient safety and quality of care movement in establishing a vocabulary and a greater urgency for patient advocacy efforts
• To discuss the primary goals of patient advocacy: patient-centered care, patient safety systems, and patient involvement and leadership in healthcare design, delivery, and access
• To describe the different levels of the advocacy continuum using an ecological framework

Patient advocacy is often borne of personal necessity. A woman with ovarian cancer researches experimental treatment options, finding one that puts her cancer into remission. The mother of a child with autism learns to navigate the complex healthcare system, coordinating the many specialists involved in her child’s care. A physician double-checks the tests ordered by a colleague for his aunt and, in doing so, identifies a misdiagnosis. These examples are only a few of the ways patients and their family members advocate for their own healthcare quality in the face of a system that is often frustrating, fragmented, and even dangerous.

Not surprisingly, many of these patient advocates envision a better system, one in which patients have access to high-quality information when they need it, services are better coordinated, and medical errors are avoided through careful surveillance. In some cases, the desire to prevent others from reliving their own frightening experience is so powerful that patients and their loved ones are inspired to work for broader change. For example, they may establish online support groups to inform and assist other patients, develop medical curricula to improve patient–provider
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communication, or found nonprofit organizations devoted to organizing patient groups and promoting their interests in public policy. The shift from personal, or “case,” advocacy to class advocacy on behalf of a larger group is the basis for many of the quality improvement efforts undertaken in recent years and is a primary concern of this book.

Patients, however, are not alone in seeking to change the status quo in healthcare. Numerous professionals have also recognized the need to make the healthcare system more responsive to patients’ needs. Physicians, frustrated by the recalcitrance of chronic disease, create educational materials for low-literacy patients to increase their involvement in managing their diabetes. Researchers develop tools to aid providers in eliciting their patients’ care preferences. Hospital administrators institute patient representative programs to help patients successfully navigate the hospital system. Attorneys explore the use of mediation, rather than litigation, as a tool for asserting patients’ rights. In such ways, professionals can also become patient advocates. Often swimming upstream against their own professional and organizational norms, these advocates help provide safer and more satisfying care, while at the same time changing the systems-level problems that generate the need for advocacy in the first place.

Subsequent chapters explore each of these examples of patient advocacy in greater depth; they are presented here to illustrate the breadth of the subject. Patient advocates share an interest in improving patient safety and patient experience, but they hail from a wide range of personal and professional backgrounds. In fact, this diversity has been a barrier to organization and collaboration. Patient advocates often report their greatest frustration to be the feeling that they are working in isolation. As challengers to the status quo, they do not always feel comfortable in their given roles as patients or healthcare professionals, but neither do they have easy access to other reform-minded people who could share lessons learned and provide much needed information and support.

The purpose of this chapter is to identify some of the primary forms of patient advocacy and to show how, despite their differences, many advocates are now working to realize the goals of patient-centered care, patient safety, and patient involvement. We discuss traditions of patient advocacy related to specific health topics such as palliative care and breast cancer as well as those that have arisen in particular professions such as nursing. We also examine the contributions of the patient safety movement. With *To Err Is Human*, the Institute of Medicine (IOM) succeeded in creating
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a sense of urgency about systemic problems underlying the need for patient advocacy (2000). A subsequent report, *Crossing the Quality Chasm*, furthered this discussion by describing a gold standard of healthcare, one characterized by principles such as patient centeredness, equity, and timeliness (2001). With these reports, the issue of healthcare quality gained national prominence and gave patient advocacy a new focus and imperative. In this environment, the time is ripe to discuss ways in which patient advocacy shows important signs of coalescing to become a focus of action and research.

In addition to discussing the origins of patient advocacy, this chapter sets forth a framework that can be used to understand better who the advocates are and how their work is interconnected. Beginning at the level of the individual patient, we show how advocates provide patients with the information and support they need to navigate the healthcare system and to make informed decisions about their health. At the interpersonal level, we examine how advocates work to improve patient–provider communication and to maximize opportunities for peer support. We then broaden our focus to examine the organizational and policy levels where advocates are changing hospitals, medical schools, and nonprofit agencies so that they are more accountable to the patients they serve. Using an ecological framework such as this one offers a more holistic view of advocacy that, in turn, enables patient advocates to identify potential supporters and collaborators more easily.

TRADITIONS IN PATIENT ADVOCACY

To speak of traditions of patient advocacy may sound premature in the context of an emerging area of inquiry; nevertheless, it has a history, and it is possible to identify the “roots” of patient advocacy in several contexts. The “helping professions” of nursing and social work, for example, have a long history of advocacy, connected as they are with the day-to-day work of caring for patients (Mallik, 1997). Other forms of patient advocacy are associated with particular kinds of care, such as mental health or palliative care, in which patients’ autonomy may be in jeopardy (Casarett, Karlawish, & Byock, 2002). A third and closely related type of advocacy is that of activists, often disease survivors, who work to improve healthcare for people marginalized by socially stigmatizing diseases.
Whether in regard to HIV/AIDS or breast cancer, patient advocacy in this context is often tied to broader social movements such as the gay rights, women’s, or consumer health movements. Examples of each type of advocacy help illustrate patient advocacy’s meanings and complexity.

Professional Roles: Nursing

All health professions are founded on the desire to care for patients, but the practice of nursing is particularly salient to the concept of patient advocacy. As intermediaries between the world of patients and medical institutions, nurses have been among the first in healthcare to define their professional role in terms of advocacy, and as a result, the nursing literature is rich in its discussion of the concept of patient advocacy, its moral underpinnings, and its practice. The literature suggests that nurses in the United States increasingly embrace patient advocacy as a professional role (Mallik, 1997). Although definitions of nursing-related advocacy vary, they tend to center on the nurse’s role in protecting patients’ autonomy (Kubsch, Sternard, Hovarter, & Matzke, 2004; Mallik, 1997). For example, a concept analysis by Moyra Baldwin (2003) identifies three “essential attributes” of patient advocacy in nursing: (1) valuing patients’ right to self-determination, (2) apprising patients though a combination of education and advising so that they may take part in decision making, and (3) interceding for patients with others, including family members and physicians, to ensure that patients’ wishes are honored. Challenges to patient advocacy in nursing include the lack of formal training for advocacy and the risk of alienating other members of the healthcare team, particularly physicians (Grace, 2001; Mallik, 1997). Despite these concerns, many leaders in nursing consider patient advocacy to be a central goal of their profession, and the conceptual work accomplished by nurses is a valuable resource for others as they work to understand and develop advocacy roles within their own professions (Mallik, 1997).

Types of Healthcare: End of Life and Palliative Care

In addition to its professional origins, patient advocacy has roots in particular areas of healthcare, such as end of life care. As in the nursing pro...
fession, advocates in end of life and palliative care are often concerned with protecting and extending patients’ comfort and autonomy. Leaders in the field emphasize (1) open communication between patients and providers about care preferences, (2) the importance of cultural and spiritual dimensions of care, and (3) the need for adequate pain management (IOM, 1997).

Palliative care adds to our understanding of patient advocacy in that these concerns have led to the development of new care models. In the 1970s, advocates in end of life care established hospice programs designed to offer comprehensive services for patients very close to death (Byock, 2000). In this model, physicians and nurses joined families, religious and spiritual practitioners, volunteers, and others in a coordinated effort to minimize patients’ suffering as they progressed through a natural stage of life (Byock, 2000). Today, palliative care advocates continue to face challenges in integrating models such as hospice into the healthcare system (Byock, 2000), but their success in designing and disseminating the hospice model illustrates advocates’ abilities to redesign the healthcare system at an organizational level to provide more holistic, satisfying care.

Activism: Breast Cancer

Activism represents a third tradition in advocacy. As several chapters in this book illustrate, breast cancer activism is one of several powerful examples of the potential for patient advocacy (Davenport-Ennis et al., 2002). Breast cancer patients and survivors have helped change how clinicians approach this once-stigmatizing disease; advocacy efforts have resulted in greater transparency in patient–provider communication as well as changes in treatment guidelines with less invasive lumpectomies replacing radical mastectomies (Ganz, 1995). Through awareness campaigns, fundraising, lobbying, and coalition building, advocates have also pursued broader goals; following the lead of AIDS activists before them, they have increased access to screening and treatment services (Earp et al., 2002), secured funding for research, and introduced patients as experts in the process of designing and conducting breast cancer research (Lerner, 2002). Efforts such as these lend a new meaning to the idea of patient autonomy, involving patients as both the recipients and the source of advocacy.

Breast cancer activism is also important because it shows how patient advocacy is related to broader social movements. In the case of breast...
cancer, the women’s health movement and the consumer movement helped create the conditions in which survivors could unite to confront the medical establishment (Lerner, 2002). The challenges of patient advocacy in this context are similar to those of other social movements and include sustaining public interest and support, building coalitions and other collaborative relationships, and securing funding (Davenport-Ennis et al., 2002).

Nursing, palliative care, and breast cancer activism are only three of many overlapping advocacy traditions, but each illustrates themes that continue to be important in patient advocacy today. First, advocates believe patients’ rights to autonomy are paramount; echoing well-established ethical codes such as the Belmont Report, advocates argue from a rights-based perspective that every effort should be made to keep patients informed of their options and involved in their care. Second, change is often needed at the organizational level to ensure that medical and research institutions meet the needs of traditionally vulnerable groups such as children, the mentally ill, those with disabilities, and those at the end of life, as well as underserved groups such as ethnic minorities. Third, patients themselves are an important source of this change, and their approach may be confrontational, as in the case of early breast cancer or AIDS activism, or collaborative, as with more recent breast cancer advocacy efforts in which patients have been integrated to varying extents into research review boards (see Chapter 17). These themes, of course, are broad, but they gain greater clarity in light of a fourth source of patient advocacy, the patient safety movement.

THE MOVEMENT FOR PATIENT SAFETY AND HEALTHCARE QUALITY

Medical researchers have studied medical error and iatrogenic injuries for decades, but only recently did the subject of patient safety gain widespread attention. In 2000, the IOM published an alarming report on medical error, To Err Is Human: Building a Safer Health System. In that report, the Committee on the Quality of Health Care in America extrapolated the findings of two prominent Harvard studies to illustrate the scope of preventable “adverse events,” otherwise known as medical errors. These included mistakes in prescribing or administering prescription drugs, poor surgical technique, or failure to identify diagnosable illnesses...
The report captured the attention of the scientific community as well as the popular media by estimating that between 44,000 and 98,000 people die each year in the United States because of preventable medical errors (IOM, 2000).

In addition to stating the problem, the IOM committee set an ambitious goal of cutting medical error deaths in half in a 5-year period. In making recommendations toward this goal, the committee emphasized that “the problem is not bad people; the problem is that the system needs to be made safer” (IOM, 2000, p. 49). For example, a pharmacist who reads hand-written prescriptions will almost inevitably misinterpret a physician’s handwriting every once in a while, resulting in potentially fatal prescription drug errors. From the point of view of the IOM committee, the fault in this scenario lies not so much with the pharmacist, as with the procedure of handwriting prescriptions. Such errors could be avoided by changing the system to one in which prescriptions are keyed in to a patient’s electronic medical record and then printed out. In accordance with this systems-level, nonpunitive, nonreductionist perspective the committee’s recommendations focused on both mandatory and voluntary reporting of medical errors and increased systems analysis, not on greater scrutiny of individual providers.

The IOM’s famous “body count,” although hotly contested by some, was convincing enough to inspire action by many (Levin, 2005, p. 91). The federal government, for example, called on the Agency for Healthcare Research and Quality (AHRQ) to step up patient safety efforts at the national level (Levin, 2005). New organizations such as the Leapfrog Group and the American Medical Association’s National Patient Safety Foundation were also established (Levin, 2005). At the same time, medical organizations across the country investigated technologic solutions such as the adoption of electronic medical records to the systems-level problems identified by the IOM committee (Leape & Berwick, 2005). The IOM committee’s goal has not yet been met. Indeed, as recently as 2006, the IOM’s newest report in the patient safety area, Preventing Medication Errors, indicated that anywhere from 380,000 to 450,000 preventable adverse drug events take place in hospitals each year, with another estimated 800,000 adverse drug events occurring in long-term care facilities. Nevertheless, To Err Is Human clearly conferred a new legitimacy on efforts to improve the healthcare system, giving would-be reformers the quantitative evidence they needed to demand change (Stelfox, Palmisani, Scurlock, Orav, & Bates, 2006).
Perhaps even more important, however, to galvanizing the patient safety movement was a second IOM report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, published in 2001. In that document, the committee addressed the broader topic of healthcare quality, including not only issues of patient safety but also those of patient experience, cost, and access to services. Establishing six “aims” for the healthcare system, the committee identified the characteristics most important to healthcare quality. They envisioned a system described as (1) *safe*, protecting patients from medical error; (2) *effective* so as to avoid both under-use and over-use of services; (3) *patient centered*, meaning that care is anchored in patients’ values; (4) *timely*, providing services when they are needed so as to prevent more serious problems later on; (5) *efficient* in the use of material and human resources; and (6) *equitable*, so as to provide quality care to all people regardless of their gender, ethnicity, or socioeconomic status (IOM, 2001, pp. 5–6). Based on these six patient-centered aims, the committee made recommendations for federal agencies, healthcare organizations, and healthcare purchasers (IOM, 2001).

One of the most striking aspects of *Crossing the Quality Chasm* is the report’s emphasis on patient experience and patient authority. The concept of patient-centered care as one of the committee’s six aims is the most obvious example; this concept is defined in the report as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensure[s] that patient values guide all clinical decisions” (IOM, 2001, p. 6). The ensuing chapters in this volume offer extensive examples of what it means to respect and respond to such preferences, needs, and values. In addition to overarching aims, the committee also set forth 10 “rules” for reforming the healthcare system. Patients also feature prominently in this context. Rules include “customization [of care] based on patient needs and values,” “the patient as the source of control” in decision making, “shared knowledge and the free flow of information” between patient and providers, and “the need for transparency” (IOM, 2001, p. 8). Finally, the committee asserted a role for patients in enacting these aims and rules, naming patients, along with healthcare organizations, purchasers, and providers, as one of the stakeholders responsible for change. If *To Err Is Human* emphasized the importance of systems analysis in healthcare, *Crossing the Quality Chasm* established the patient at the center of those systems.

The IOM reports have a number of important implications for patient advocacy. First, they have provided advocates with the data needed to
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prove that widespread structural problems do exist in the healthcare system and that these problems are serious, resulting in the loss of thousands of lives each year. Second, the reports have illustrated the need to think beyond the culpability of individual providers to consider systems-level factors that determine healthcare quality. Third, the IOM has established, or at least popularized, a vocabulary and an approach that have helped patient advocates articulate their goals. Patient-centered care is now an often-used term among patient advocates, even in the midst of debate about how exactly to conceptualize and implement it. Finally, the IOM reports may be credited more generally with bringing awareness to issues important to patient advocates, thereby drawing more people and funding to their efforts. That the healthcare system is frustrating and dangerous has, in effect, been transformed from experiential or anecdotal knowledge to an empirically testable, scientific knowledge that is accepted by those both inside and outside of the medical establishment.

OVERARCHING GOALS OF PATIENT ADVOCACY

The various “traditions” of patient advocacy reveal commonalities that are not surprising in light of the widespread systems-level problems identified by the IOM. The stories of individuals who become advocates out of personal necessity are replicated across a number of professions and disease foci. Despite their different origins, patient advocacy efforts are primarily inspired by three main goals: patient-centered care, safer medical systems, and greater patient involvement in healthcare delivery and design.

Patient-Centered Care

Perhaps no other term evokes the aims of patient advocacy as fully as patient-centered care, a concept that has drawn considerable attention from patients and professionals alike. Though definitions vary, many begin with the IOM’s aforementioned emphasis on patient preferences and values. The Picker Institute has furthered this definition with research that identifies seven dimensions of the concept: (1) “respect for patients’ values, preferences, and expressed needs,” (2) “coordination and integration of care” among providers and healthcare institutions, (3) “information,
communication, and education” tailored to patients’ needs, (4) “physical comfort,” especially freedom from pain, (5) “emotional support” to reduce the fear and worry associated with illness and treatment, (6) “involvement of family and friends” in caregiving and decision making, and (7) planning for “transition and continuity” to ensure patients continue to heal after they leave the hospital (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993, pp. 5–10). These dimensions illustrate the assumption underlying patient-centered healthcare as both a personal and social process aimed not solely at treating disease, but also at promoting a more holistic well-being through supportive interpersonal, cultural, and organizational interactions.

At the same time, the term “patient-centered care” is not without controversy. Although most advocates would agree with the dimensions outlined by the Picker Institute, some take issue with the name itself, preferring instead “person-centered,” “family-centered,” or “relationship-centered” care. Others feel that “patient-centered care” is a concept that has been co-opted to some degree by those with a business interest in healthcare and may be too easily confused with terms such as “consumer-centered” or “consumer-driven” healthcare. This area of discussion reflects a broader debate about the terminology of patient advocacy that must be considered carefully by patients and professionals as they define their own work (Textbox 1.1).

**Safer Systems**

A second goal of patient advocacy is to establish systems that will ensure patient safety. As defined by Longo, Hewett, and Schubert, these systems are the “various policies, procedures, technologies, services, and numerous interactions among them necessary for the proper functioning of hospital care” (2005, p. 2859). Patient safety systems, in other words, are diverse, and they may extend to any healthcare setting from hospitals to pharmacies to long-term care facilities. Patient safety systems include (1) **technological innovations** such as electronic medical records and prescription tracking systems that improve the accuracy and availability of medical information, (2) **procedures** such as the marking of surgical sites that introduce reminders and reduce chances for miscommunication, and (3) **policies** that ensure medical errors, or even “near misses,” are reported, analyzed, and addressed (Longo et al., 2005). Even though many systems
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Textbox 1.1 Advocacy Terminology: What Is in a Name?

As social reformers, patient advocates are often interested in updating both popular and professional language to better convey the values they aim to support. The very language that we use frames how we think about a set of problems, defining and limiting categories of knowledge. Since at least the 1970s, healthcare reformers have argued about the appropriate words to use for people who receive care. For many, the term *patient* evokes the image of a powerless layperson submitting passively to medical authority (Neuberger, 1999). Others point out that the term is poorly suited for describing people who are essentially healthy, but require health-related services, such as people living in long-term care facilities, pregnant women, and others (Herxheimer & Goodare, 1999). Some feel that these connotations of passivity and illness are serious enough to warrant abandoning the term *patient* altogether (Neuberger, 1999).

Alternatives to *patient* include *partner*, *consumer*, *client*, and *user*, each of which carries its own connotations and limitations. *Partner* is effective in communicating shared power, but is not health specific and requires additional modifiers to distinguish between the person receiving services and the professional providing them. On the other hand, *consumer*, *client*, and *user* have commercial connotations, conceptualizing healthcare as a commodity best regulated through market forces rather than as a personal need or right (Herxheimer & Goodare, 1999). In the end, context and tradition often decide word choice. For example, *client* is the preferred term of certain professions such as psychology and social work, whereas *consumer* is often used to refer to patients collectively, especially at the level of policy advocacy efforts. Interestingly, after weighing the merits of these various terms for years, advocacy educators at Sarah Lawrence College opted finally for “person.” Depending on context, this book uses many forms of the term: patient, partner, consumer, client, and person.

Semantic debate extends to other advocacy terms, including *patient-centered care*. Advocates who work in residential settings, for example, may favor *person-centered care*, possibly a more appropriate term for healthy people. Pediatric advocates, on the other hand, use *family-centered care* to emphasize the social dimension of care they feel is so often lacking in traditional medical practice.

These distinctions are of no small consequence to a text devoted to *patient advocacy*, a conflicted term that gives rise to debate. One particular interest is how the term is distinct from other, closely related concepts. For the purposes of this text, patient advocacy has been defined very broadly to include interventions targeting individual empowerment, interpersonal interactions, organizational and cultural change, and policy development related

(continued)
solutions are technical and organizational in nature, suggesting a throw-back to technocratic rather than social solutions to healthcare problems, they are based on a “culture of patient safety” in which healthcare administrators, providers, and patients value and promote safety (Clancy, 2005, p. 277). Like patient centeredness, patient safety implies an attitudinal shift toward healthcare governed by a set of values focused on human beings within their social milieus.

**Patient Involvement in Healthcare**

A third goal of patient advocacy, implicit in both patient centeredness and patient safety, is the desire to give patients a greater voice in healthcare. Patient advocates recognize that the biomedical orientation of the U.S. healthcare system often champions the scientific knowledge of healthcare professionals while undervaluing the lay knowledge of patients. At the level of the individual medical encounter, patients are not encouraged often enough to be partners in their own care, resulting in the loss of valuable information as well as motivation on the part of the patient to contribute to and follow treatment plans. Advocates wish to improve patient–provider communication by “activating” patients, educating providers, and creating models of patient-centered communication.

**Textbox 1.1 Advocacy Terminology: What Is in a Name? (continued)**

to healthcare delivery and design. An even broader term, however, is *health advocacy*. It encompasses these dimensions as well as efforts to impact determinants of health outside the healthcare system. *Health advocacy* implies community and environmental efforts directed at, for example, lead paint abatement in low-income communities. Distinguishing patient advocacy from similar concepts, although frustrating at times, can help scholars and practitioners reach a more precise understanding of *patient advocacy*, even as we recognize the limitations of the vocabulary we use.

Given the nature of language and meaning—that is, the ways in which a word has the power to categorize and limit—variants in terminology will undoubtedly persist. With this recognition, this volume aims to recognize the significance of terminology, to demonstrate an understanding and respect for the tradeoffs made in choosing one term over another, and to introduce readers to different advocacy dialects.
(Chapters 7, 8, and 9). The rise in chronic diseases such as diabetes is creating an even greater need for such patient engagement as more and more healthcare becomes self-care, which must be managed by the patient outside of the healthcare system.

The neglect of “patient voice” has broader consequences as well. Patients have a valuable perspective to offer those in medical education and medical research. When given the opportunity, patients can, for example, develop and teach medical school curricula in patient–provider communication, compose and pretest health education materials and consent forms to improve their readability and relevance to lay people, and serve alongside scientists on research review boards. True patient participation is rarely invited in these ways, but patient advocates hope to correct this imbalance by changing institutional cultures so that patients’ contributions become more valued by and accessible to health professionals.

Patient or consumer voice is often similarly underrepresented in health policy and administration, leading to healthcare organizations and public policies that do not serve public interests as effectively as they might (Davis, Schoenbaum, & Audet, 2005). This danger is particularly acute for minority groups and low-income communities whose access to even the most basic of healthcare services is often at stake. Improving healthcare access involves many factors central to patient advocacy, including making healthcare more affordable (e.g., by enacting state or federal policies that extend health insurance to the over 45 million uninsured); reducing barriers to the use of medical institutions (e.g., by increasing hours of operation and providing translation services); and reaching out, through lay health advisor and patient navigator programs, to populations who have been alienated by the healthcare system. Patient advocates believe that patient input is crucial to tackling issues such as these, and they seek to mobilize patients through public awareness campaigns and grassroots organizing so that patients’ voices are heard.

The three goals of patient advocacy outlined here (i.e., patient-centered care, patient safety, and patient involvement) are broad and have the potential to overlap. For example, increasing patient involvement in healthcare is often identified as an essential part of both patient-centered care as well as the improvement of patient safety systems. Although the distinction among the three goals is in some ways artificial, conceptualizing patient advocacy as the intersection of patient-centered care, patient safety, and patient involvement helps us more easily map the intellectual streams we perceive as contributing to these related sets of endeavors.
In the case of each goal, patient advocacy occurs along a continuum from individual medical encounters to organizational and systems efforts to policy and grassroots initiatives. Like the problems they are meant to address, patient advocacy efforts are designed to be widespread and systemic in nature.

**MAPPING THE ADVOCACY CONTINUUM: AN ECOLOGICAL FRAMEWORK**

Given the breadth of patient advocacy’s goals, it is not surprising that advocacy’s roles and methods, not to mention its actors, are diverse and resist being categorized under one umbrella. Nevertheless, developing a “taxonomy” of patient advocacy is an important first step toward fostering understanding and collaboration among various stakeholders. The social ecological framework is a useful heuristic often employed in public health and may serve as a helpful conceptual framework for mapping the advocacy continuum (McLeroy, Bibeau, Steckler, & Glanz, 1988). The social ecological framework divides interventions by their level of influence and is well suited for addressing the multiple modalities of patient advocacy. By considering advocacy at the individual, interpersonal, organizational, and policy levels, as delineated by the social ecological framework, we can map the patient advocacy continuum in a way that increases
our understanding of who advocates are and how their work is interrelated (see Figure 1.2).

The Individual Level: Informing Patients

The social ecological framework begins at the level of the individual and considers interventions that target the personal beliefs, attitudes, and knowledge needed to achieve health. Many efforts examined in this volume begin with these “individual level” determinants, both patients’ own efforts to educate and orient themselves, and with other efforts that seek to bolster patients’ knowledge and confidence so that they may more fully participate in their own care. Sometimes falling under the rubric of “self-help,” patient advocates may develop patient education materials that address a particular disease or that more generally help patients navigate the healthcare system more safely and effectively. Patients’ literacy and access to information are related concerns for both practitioners and researchers, especially as chronic diseases force patients to take an ever greater role in the treatment process (Chapter 8).

In the realm of “individual-level” advocacy, e-health is a dynamic new area of interest to patient advocates, with recent studies showing that as

![Figure 1.2 Patient Advocacy from a Social Ecological Perspective](image-url)
many as 80% of Internet users seek health information online (Fox, 2005). Sites devoted to informing patients include those sponsored by nonprofit and government agencies (e.g., AARP and Agency for Health Care Research and Quality (AHRQ)), well-known professionals (e.g., Tom Ferguson’s DocTom.Com and Alan Greene’s DocGreene.Com), and patients themselves (e.g., Karen Parles’s lungcanceronline.org). The content of these sites is as diverse as their sponsors and includes information and advice related to (1) choosing a health plan, medical center, or healthcare provider; (2) learning about diseases and treatment options; (3) preventing medical error and increasing participation in treatment decisions; and (4) understanding the lived experience of patients as they face specific illnesses. Although only a small sampling, these resources demonstrate the wide range of advocacy efforts devoted to giving patients the knowledge that they need to become actively involved in their own care (Chapter 4). Of course, e-health interventions are not limited to the “individual level” alone. In addition to providing information, some e-health efforts focus on helping patients cultivate interpersonal relationships with other patients and providers through, for example, e-mail or online support groups.

The Interpersonal Level: Supporting and Empowering Patients

In addition to their own beliefs and knowledge, people are often influenced by others in their social network. The second “level” of the social ecological framework therefore focuses on the interpersonal interactions that support health, such as advice giving, emotional support, and the provision of resources and other help. In the case of patient advocacy, the most relevant interpersonal relationships may be those between patients and their family members and friends, their healthcare providers, and other patients in similar circumstances. Advocacy efforts at the interpersonal level are devoted to connecting patients to people who can be most helpful to them and to improving the quality of communication and support given.

Patient–provider communication is probably the most well-studied example of patient advocacy efforts at the interpersonal level. In particular, advocates are interested in advancing patient-centered models of communication in which providers take not only a biomedical interest in
patients’ physical symptoms, but also consider psychosocial aspects of care, including the social, cultural, and financial factors that impact patients’ health (Mead & Bower, 2000). Both medical researchers and patients themselves have worked to develop models of patient-centered communications, such as motivational interviewing, and then have trained providers in using these methods (Chapters 3, 6, 7, and 9). At the same time, advocates are pushing for the adoption of new technologies in electronic medical records that would better capture this patient information, allowing for greater continuity of care between visits and among providers.

Patient advocates also recognize the importance of nonmedical relationships. Family members and friends, for example, provide patients with much needed emotional and instrumental support. They also have an important role to play in asserting patients’ rights, preventing adverse drug events or other medical errors, and helping patients understand and follow treatment regimens. Patient advocates help patients benefit from the involvement of friends and family members by encouraging these people to become involved in the care process and by addressing barriers, such as limited visiting hours or attitudes of healthcare employees, that make it difficult for loved ones to act as advocates. Patient advocates also work to connect patients with other lay people, such as disease survivors, who can help orient and support patients; these interventions may take the form of online or in-person support groups, hospital-based peer navigation programs, or community outreach efforts (Chapters 3, 4, and 5). In these ways, patient advocates support and expand patients’ social networks to provide care that is socially specific and culturally appropriate.

The Organizational and Community Levels: Transforming Culture

Social networks are organized more broadly by community and organizational structures, and the third level of the social ecological framework addresses interventions aimed at these macro-level environments. In patient advocacy, organizations that determine the patient centeredness and safety of healthcare include hospitals, professional associations, medical and other health science schools, and advocacy-related community organizations. These organizations play a major role in governing
how and where healthcare is practiced as well as who may participate in the process of giving and receiving care. More generally, these organizations are responsible for establishing a tone or culture that can either support or discourage patient centeredness, patient safety, and patient involvement.

Not surprisingly, hospitals are the center of many patient advocacy efforts, and patient advocacy in this setting includes efforts to establish new models and systems. Hospital administrators and health services researchers, for example, develop and implement hospital models of patient-centered care that engage patients by increasing the accessibility of medical information, improving the navigability and appearance of hospital buildings, and offering greater access to complementary and alternative therapies (Chapters 11 and 13). At the same time, others work to make hospital settings more conducive to patient safety by instituting systems that prevent error as well as those that monitor and analyze errors that do occur. Patient advocates are among those responsible for developing these systems and for helping to get them adopted (i.e., building support among patient and hospital administrators, aligning financials and prestige-related incentives, training hospital providers and staff, and organizing patient and consumer support) (Chapter 10). In these ways, patient advocates attempt to change the entire organizational culture of medical institutions from hospitals to medical schools to professional associations so as to bring them into better alignment with the goals of patient advocacy (Chapter 12).

One long-standing example of patient advocacy at the organizational level is the patient representative program. In these hospital-based efforts, representatives are assigned to patients who need assistance in navigating the hospital system, especially with regard to voicing and addressing complaints related to their care (Ravich & Schmolka, 1993). Patient representatives are meant to be problem solvers who help personalize care and assert patient rights. They may range from professional representatives who are employed by the hospital to trained volunteers who serve on a part-time basis. Although critics have argued that such hospital-sponsored efforts present a serious conflict of interest, patient representative programs have become a common feature of hospitals across the country and are a well-known quality improvement tool (Ravich & Schmolka, 1993).
The Policy Level: Translating Consumer Voice into Policy and Law

In addition to organizational rules and procedures, the social ecological framework recognizes the importance of broader policies and laws. In patient advocacy, important policies are those that (1) control access to care; (2) regulate healthcare organizations, especially with regard to patient safety surveillance; and (3) protect healthcare consumers. Patient advocates work to influence policy making through activism, ombuds programs, and political lobbying so that lay people have a voice in a healthcare system otherwise dominated by the beliefs and practices of health professionals and business interests.

Grassroots organizing is one important example of patient advocacy at the policy level. Advocates representing vulnerable communities such as children, older adults, and the uninsured are responsible for gauging the interests and needs of their constituencies, communicating and promoting these priorities to policy makers, and enforcing the regulation of policies once they have been established (Chapters 15, 16, and 17). Additionally, advocates work to protect consumers’ access to information and promote a higher level of truth in advertising (Chapter 14). In these ways, patient advocates address the macro-level forces that govern organizations, interpersonal interactions, and individual health behaviors.

The different levels of the social ecological framework are useful for categorizing advocacy efforts, allowing for an understanding of patient advocacy that moves beyond the activities of individuals helping patients move through complex health systems. The framework also suggests how levels are related. The social ecological framework is based on the premise that health promotion efforts can be significantly strengthened by intervening at multiple levels simultaneously (McLeroy et al., 1988). For example, patients who have been “activated” through interventions at the individual level are better able to take part in patient-centered communication fostered by interventions at the interpersonal level. At the same time, improved interpersonal communication results in more activated patients. These interactions can only happen to the extent that organizations and policies encourage patients to access the healthcare system in the first place, but activated patients and physicians are more likely than others to participate in the organizational and political processes that determine access to care. In other words, gains at one level of advocacy carry over to other levels, and this idea of reciprocal determinism has
important implications for patient advocacy (McLeroy et al., 1988). The social ecological framework suggests the ways in which the multiplicity of patient advocacy efforts are a strength, rather than a liability, and that better communication and coordination among advocates working at different levels may have a synergistic effect that benefits everyone involved (see Table 1.1).

**PATIENT ADVOCACY, AN EMERGING FIELD?**

This text is based on a social ecological conceptualization of patient advocacy that includes individual, interpersonal, organizational, and policy-level components. Subsequent chapters explore these levels of advocacy in greater depth, showing that from patients to healthcare providers to nonprofit leaders to researchers, every stakeholder in the healthcare system has the potential to contribute to efforts to promote patient-centered care, patient safety, and patient involvement. This view is supported by patient advocacy leaders, as this book defines them, from every level of the healthcare system, as evidenced by advocacy-related literature as well as recent survey research (see Textbox 1.2) (Casarett et al., 2002; Davenport-Ennis et al., 2002; Ganz, 1995).

Although not all stakeholders perceive patient advocacy as a movement, much less a field, this volume makes a case that this collection of efforts points to the emergence of a distinct professional area. As the chapters that follow show, advocates increasingly recognize the need to collaborate around their shared goals and challenges (Chapter 2). As a result, individual advocates are beginning to coalesce into broader networks and organizations. At the same time, roles for advocacy are becoming more numerous, both for professional patient advocates such as patient representatives and those in other professions such as medicine and law who wish to specialize in advocacy (Chapters 19 and 20). A corresponding increase in interest in advocacy education is also evident, as shown by the growing number of graduate-level courses devoted to the topic (Chapter 18). From a social ecological perspective, these efforts to unify and coordinate patient advocacy efforts may provide the external and internal pressure needed to significantly improve healthcare quality.
Table 1.1 Patient Advocacy Intervention Matrix: Examples by Level of Influence

<table>
<thead>
<tr>
<th>LEVEL OF INFLUENCE</th>
<th>Patient Advocacy Goals</th>
<th>Individual</th>
<th>Interpersonal</th>
<th>Organizational and Community</th>
<th>Policy and Consumer Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-Centered</td>
<td>• Provide patients with information about illness and treatment options</td>
<td>• Engage family members and friends in care</td>
<td>• Design organizational models that support patient-centered care</td>
<td>• Support efforts to ensure access to care</td>
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<tr>
<td>Care</td>
<td>• Help patients assess and choose medical care facilities, providers</td>
<td>• Connect patients to peers through support groups, peer navigator programs</td>
<td>• Change hospital rules and physical environments to better support family involvement</td>
<td>• Conduct assessments of medical centers, health-care plans for consumer reports</td>
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<tr>
<td></td>
<td>• Increase patients' access to information through written, video, or electronic resources</td>
<td>• Develop models and tools of patient-centered communication</td>
<td>• Reward providers for practicing patient-centered care</td>
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<tr>
<td></td>
<td>• Increase readability and cultural relevance of patient education materials</td>
<td>• Train providers in patient-centered communication</td>
<td>• Coordinate patient representative and lay health advisor programs that help both existing patients and those facing barriers to accessing care</td>
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<tr>
<td>Patient-Organizational Policy and Advocacy Goals</td>
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<tr>
<td>Policy</td>
<td>• Increase patient access to information through written, video, or electronic resources</td>
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<td></td>
<td>• Increase readability and cultural relevance of patient education materials</td>
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<tr>
<td>Community</td>
<td>• Engage family members and friends in care</td>
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<td></td>
<td>• Connect patients to peers through support groups, peer navigator programs</td>
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<td><strong>LEVEL OF INFLUENCE</strong></td>
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<td><strong>Patient Advocacy Goals</strong></td>
<td><strong>Individual</strong></td>
<td><strong>Interpersonal</strong></td>
<td><strong>Organizational and Community</strong></td>
<td><strong>Policy and Consumer Health</strong></td>
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<td><strong>Patient Safety</strong></td>
<td>• Engage patients in patient safety practices (e.g., verifying medication doses)</td>
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<td></td>
<td>• Inform patients and providers about risk of medical error</td>
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<td></td>
<td>• Engage patients in care process</td>
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<td><strong>Patient Involvement</strong></td>
<td>• Include patients in development and pretesting of patient education materials</td>
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<td></td>
<td>• Integrate patients in design and implementation of communication curricula for providers</td>
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<td></td>
<td>• Recruit patients and survivors to act as peer educators</td>
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<td></td>
<td>• Develop systems for capturing and addressing medical errors</td>
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<td></td>
<td>• Change medical school and hospital culture to encourage more collaborative relationships among providers</td>
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<tr>
<td></td>
<td>• Prioritize safety-related organizations for financial and political support</td>
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<td></td>
<td>• Raise awareness among consumers about the pervasiveness of medical error</td>
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<tr>
<td></td>
<td>• Organize health activism and grassroots advocacy</td>
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<tr>
<td></td>
<td>• Include patients and survivors in developing and funding research studies</td>
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</table>
Patient Advocacy, an Emerging Field?

Textbox 1.2 The University of North Carolina (UNC) Patient Advocacy Survey: What Is Patient Advocacy?

A national survey by the UNC School of Public Health explored the topic of patient advocacy. In 2005, a purposive sample of advocacy leaders from all levels of healthcare were invited to complete an online questionnaire. Respondents were asked to define patient advocacy and to identify important roles, aims, and methods related to the concept. A total of 112 respondents completed the survey, representing a response rate of 55%.

Survey respondents perceived patient advocacy efforts as involving a broad spectrum of actors from patients to providers to heads of non-profits and others.

- When asked which of seven groups “often” or “sometimes” take on the role of patient advocate, about three quarters of respondents indicated patients themselves (72%), family members or friends (81%), nurses (76%), social workers (81%), and hospital patient representatives (72%). Almost half (47%) indicated that physicians do so as well.

- The majority of respondents wished these groups were more active in advocacy efforts, with over three quarters indicating that they would like to see patients themselves (78%) and physicians (79%) take even more of a role in patient advocacy.

- The majority of respondents also felt that a “big role” or “somewhat of a role” is played by leaders of nonprofit organizations (79%), educators of patient advocates (86%), and activists and grassroots organizers (89%).

- About three quarters of respondents (71%) wished to see hospital administrators take more of a role in patient advocacy.

- Respondents indicated a number of reasons for getting involved in health-related advocacy, with one quarter (25%) citing the experience of a friend or family member as their main motivation.

Respondents rated the importance of advocacy-related goals, methods, and competencies.

- The vast majority of respondents indicated that “very important” goals in patient advocacy include quality improvement and patient safety (84%), more patient-centered care (86%), improved patient-provider communication (88%), and increased access to care (79%).

- Over half of our respondents (57%) reported that patient/consumer education is a method “often” used by patient advocates. In terms of methods that should be used more often than they currently are, about two thirds mentioned organizational change in hospitals (69%) and provider education/curriculum reform (65%).

- In terms of “next steps” for patient advocacy, over half the respondents assigned a “high priority” rating to coordinating advocacy efforts more
effectively (61%), raising public awareness about advocacy issues (59%), and training more advocates/training advocates more effectively (51%).

- In regard to advocacy competencies, respondents most often assigned a “very important” rating to communication skills (86%) and an understanding of the patient’s perspective (83%).

Respondents defined patient advocacy via four themes: (1) taking a multilevel approach that includes both individual- and systems-level advocacy, (2) increasing patient power by facilitating patients’ education, involvement in decision making and ability to navigate the healthcare system, (3) changing hospital and provider culture to be more patient centered, and (4) improving healthcare quality, particularly in regard to patient safety and access to care. A few illustrative responses included the following:

- **Patient advocacy is supporting and empowering patients to make informed decisions, navigate the system to get the healthcare they need, build strong partnerships with providers while working toward system improvement to support patient-centered care. Patient advocates are dedicated first and foremost to the well being of the patients they serve.**

- **Assisting people (either as case advocacy on behalf of individuals or class advocacy on behalf of a group) with the process of receiving healthcare, maximizing their health, and ensuring that all people have access to safe and comprehensive healthcare.**

- **Standing with patients to assist them in meeting their needs by intervening at various levels of the health and social care system.**

- **Efforts to ensure that patients have the information and the self-determination they need so that patient needs are forefront in decisions about patient care.**

- **Patient advocacy is the bilateral appreciation that the focus of medical intervention should be “patient centered.” This includes the sharing of decision making, risks, cost effectiveness, treatment regimens, goals, and expectations. This must be implemented with an appreciation of the individual patient and physician in the global context of healthcare.**

Although this cross-sectional study of a relatively small, purposive sample of people already involved in patient advocacy work cannot be seen as the defining standard in what we are positing as the emerging field that is patient advocacy, it was useful in both confirming what policy makers and researchers have been writing about for almost a decade and suggesting directions for future research and programmatic efforts.

REFERENCES


CHAPTER 1 WHAT IS PATIENT ADVOCACY?


