

Patient Advocacy: Putting the Vocabulary of Patient-Centered Care into Action

Elizabeth A. French, MA; Melissa B. Gilkey, MPH; Jo Anne L. Earp, ScD

About seven years ago, when the University of North Carolina at Chapel Hill received seed funds from an alumnus to start an initiative on patient advocacy within the Department of Health Behavior and Health Education,^a we embarked on an effort to better define the subject area, initiate a multidisciplinary focus on this topic within the School of Public Health, and mobilize leaders to advance patient advocacy's aims, scope, and reach. Over the years, we have come to see patient advocacy as a practice aimed at improving health care quality and access, particularly with regard to patient-centeredness and patient safety, by advancing the patient's perspective. The methods of patient advocacy are varied. They encompass everything from interventions that target individual empowerment and better patient-provider communication to policy development efforts that can improve health care delivery and design. Its practitioners vary as well, from patients and family members to health care providers, hospital administrators, researchers, and policymakers. This broad definition of patient advocacy was not immediately apparent to us but rather evolved over time after reflection and research with colleagues from a wide range of backgrounds. Here we recount this process to document major ideas, tensions, and traditions that have shaped the evolution of this field and to give a context for the commentaries in this issue of the *Journal*.

Two major influences guided our work from the beginning: (1) the ideas and actions of our advocate colleagues, and (2) concepts put forth in a pair of seminal reports by the Institute of Medicine of the National Academies (IOM), *To Err is Human: Building a Safer Health System* (2000) and *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001). Together, these books point to patient-centered care as starting and ending points for improving the quality of care delivered within our nation's health care system.

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With the IOM reports in hand and with the support of a national network of advocates made up of health professionals, lawyers, heads of nonprofits, survivors of disease, and others who self-identified as patient advocates, our team at UNC: hosted two conferences, in 2003 and 2005; edited a foundational textbook;¹ conducted preliminary research on

a The Scott and June Pearson Fund for Patient Advocacy was established within the Department of Health Behavior and Health Education at the UNC Gillings School of Global Public Health by Mr. Clarence Pearson and Ms. Laurie Norris in 2000.

Elizabeth A. French, MA, is a lecturer and assistant director of academic affairs in the UNC Gillings School of Global Public Health, Department of Health Behavior and Health Education at the University of North Carolina at Chapel Hill. She can be reached at eafrench (at) email.unc.edu.

Melissa B. Gilkey, MPH, is a doctoral student in the Department of Health, Behavior and Society at the Johns Hopkins Bloomberg School of Public Health.

Jo Anne L. Earp, ScD, is professor and interim chair in the UNC Gillings School of Global Public Health, Department of Health Behavior and Health Education at the University of North Carolina at Chapel Hill.

patient advocacy questions;² and developed a graduate level seminar, now in its fourth year, that has attracted students from public health, nursing, occupational therapy, pharmacy, and social work. In doing so, we have created forums for thinkers and doers from across the nation but especially with and for advocates from North Carolina. These efforts, we believe, have helped to further codify and disseminate our collective knowledge of patient advocacy's principles, methods, and the many research questions that remain unanswered.

Our first agenda item, to develop a taxonomy of the field, proved a challenge in its own right. We quickly confronted the perception, even among ourselves, that "advocacy" is a loaded term, connoting not simply methods used to right a social wrong but a potentially biased approach fueled by enthusiasm, even self-interest, rather than evidence. Part of our agenda as scholars of patient advocacy has therefore been to bring together a body of sound information to undergird its aims while also analyzing its methods to bring attention to its ethical practice.

We quickly found that no stable definition of patient advocacy was in circulation, and that the term itself was charged with political meaning. *Patient*, we came to understand, connotes a level of passivity that many of our colleagues reject. Moreover, it may not fully capture the social and political contexts of people suffering from illness. Yet the word *client*, with its connotation of being a *customer*, much less the word *consumer*, which gestures to those who are able to shop around for their health care, seem even less adequate. For our purposes, we define *patient advocacy* as the wide range of interventions promoting patient-centeredness, patient safety, and patient voice in the health care system. Similar to those who use the term *health advocacy*, a term that embraces both patient advocacy and efforts to change health determinants outside the health care system, we take an ecological approach. We aim our work at all societal levels: at individual patients, their families, and providers; institutions such as hospitals and nursing homes; communities; and policies. Similar to our definition, our methods are broad, drawing on approaches familiar to those in the humanities (narratives as tools for understanding multiple perspectives), the social sciences (understanding the social context of illness), and those driven by the metrics of quality improvement.

Yet despite the richness that all these terms add to the conversation, we have retained the phrase patient advocacy because of the way the term *patient* captures a physical condition describing individuals in a weakened state or in need of a champion or mediator in the specific context of the health care system.³ Rendered vulnerable by illness, patients given serious diagnoses often find themselves growing disoriented when plunged into a complex medical world whose rules are confusing, whose language is alien, and whose processes are too often dehumanizing. One way patients have of coming to terms with this alienation is through their own narratives of illness—how they believe they were stricken ill, how they believe they can get better, what they fear in the course of treatment, and how they anticipate coping with their treatment

and recovery, or perhaps death. These narratives are important pieces of evidence, identifying as they do the ways our health care system can better respond to suffering. Katie Patsakham affirms this perspective in her commentary when she writes that "this unique capacity of patients to share the way in which they experience illness is a defining characteristic in the practice of medicine."

It is also a defining characteristic of patient advocacy, a term we use for the way it recognizes that the very experience of being (or having been) a patient confers an authority of its own, an authority that can create a powerful base from which to advocate. Barbara Rimer references this concept in her dedication piece, which remembers Michelle Mayer, a faculty member at the UNC Gillings School of Global Public Health, and the blog Michelle maintained in the months preceding her death. In that blog, *Diary of a Dying Mom*, Michelle wrote of her advocacy efforts to receive better care in a complex health system. She reminded readers that she made these efforts even as she struggled with constant physical pain, and even as she maintained her commitments to being an active professional, loving wife, and devoted mother of two children.

Tiffany Christensen also embodies this authority, as is clear from her commentary in which she describes her experiences as a patient advocate. Now 36 years old and a self-described "life-long patient," Christensen was born with cystic fibrosis, weathered a double lung transplant, and now makes it her life's calling to help others make the leap to activated patient. Walking readers through her own experience, and writing in a simple, direct, and personal way, she coaches others in self-advocacy through her publications and other resources.^{4,5} "I have learned that being hospitalized is not a time to relax and heal," she writes, "but rather [a time] when I must assume responsibility for steering my own health care ship. If I am too sick to stand at the helm," she continues, "I must have a friend or family member take over from me." Beverley Johnson, Marie Abraham, and Terri Shelton also represent this perspective in their commentary. They focus their work on how the practice of listening to patients and family members can inform significant change, from the redesign of hospital rooms to accommodate family member sleepovers, to the redesign of hospital gowns to ensure patients' dignity or, more radically, to policy revisions that would allow parents to attend to their children, even during emergency procedures.^{6,7}

As these examples suggest, forming a vocabulary for patient or health advocacy is more than a semantic exercise. Encoded within these word choices is a philosophy of practice that has important implications when it comes time to train those within and outside the health professions. Consonant with the work of our advocate colleagues and the contents of the IOM reports, we ultimately chose to use the term *patient* in this issue of the *North Carolina Medical Journal*, and in our textbook, for the way it refers back to individual and family experience as the driver of improvements in health care. Of utmost importance in patient advocacy work are improvements that focus not only on technically excellent care or on universal access, but on care that fully incorporates the voice and point

of view of the patient as the central actor in the unfolding scenarios we write about.

The Movement for Patient Safety and Health Care Quality: Further Defining a Vocabulary

Elsewhere in this issue, we write about the problem of patient safety as a subject in its own right, examining ways in which full disclosure of errors, accompanied by an apology, is likely to: help maintain trust among patients, providers, and institutions; reduce the likelihood that such errors will be repeated; and lessen the possibility of adversarial litigation. Catherine Cravens and Jo Anne Earp discuss this set of issues in more detail in their commentary in this issue of the *Journal*. In recent years, patient safety issues have helped frame the discourse on patient advocacy, so deserve a discussion here as well. Christensen herself references patient safety as a prime motivator for her own work. "In a country where between 44,000 and 98,000 people die each year from medical error, being an informed and alert advocate is not a choice but a necessity."

Christensen, of course, is drawing these data from *To Err is Human*, which captured the attention of the scientific community and the popular media with its aforementioned estimate of deaths due to preventable medical errors.⁸ The report generally attributed these deaths not to the malpractice of individual physicians, but instead to widespread structural problems within health care systems. The second IOM report, *Crossing the Quality Chasm*, looked at the broader topic of health care quality, including issues of patient safety, patient experience, cost, and access to services.⁹ The wider point being made here is that these watershed reports legitimized both a vocabulary and an approach to changes within health care organizations.

The *Quality Chasm* report is particularly striking in this regard, especially in its emphasis on patients. From page one, the report underscores the provision of patient-centered care as one of six fundamental reforms needed in US health care. Defined as care that is "respectful of and responsive to individual patient preferences, needs, and values, and [that] ensur[es] that patient values guide all clinical decisions,"⁹ patient-centered care took its place in the report as the driver of all six reforms it supported. The Committee also set forth 10 "rules" for reforming health care systems, in which patients were featured prominently. These rules include "customizing care based on patient needs and values;" making the patient "the source of control" in decision-making; ensuring "shared knowledge and the free flow of information" between patients and providers; and creating greater "transparency."⁹ Finally, the Committee named patients, along with health care organizations, purchasers, and providers, as essential participants in the drive towards change. If *To Err is Human* emphasized the importance of systems analysis in health care, *Crossing the Quality Chasm* established the patient—not hospitals and not providers—at the center of those systems.

Both IOM reports owe a debt to a philosophy of care

pushed forward by patient advocates over the course of many years. As the commentary by Beverley Johnson and colleagues demonstrates, it is a philosophy undergirded by the idea that, insofar as providers respect the agency of the patients they work with, they should empower those individuals to the extent possible to participate in decisions that will affect their health and well-being.

The IOM reports have significantly shaped advocacy efforts since their publication. First, they have provided advocates with the imprimatur of the IOM and with the data illustrating that widespread structural problems *do* exist in the health care system. Second, the reports confirm the need to think beyond culpability of individual providers to consider system-level factors that explain variations in health care quality. Third, the IOM has given credence to a vocabulary and an approach that helps patient advocates move forward in concrete ways towards their goals. The very term *patient-centered care*, for example, (together with sister terms such as *family-centered*, *relationship-centered*, and *patient-directed care*) is gaining greater acceptance. Finally, the reports may be credited more generally with bringing awareness to issues such as the presence of structural and cost barriers, variable communication styles, questionable control over resources, and, ultimately, medical decision-making. In 2006, then Senators Clinton and Obama lent their star power to the discussion, arguing in the *New England Journal of Medicine* that improvements in patient safety should be at the center of medical liability reform.¹⁰ These issues are central to patient advocates. That the health care system is often confusing, unpleasant, and dangerous has, in effect, been transformed from anecdotal experiences repeated by frustrated patients to a scientific knowledge base increasingly accepted by those both inside and outside the medical establishment.

Traditions of Advocacy

The patient safety movement has helped advance the agendas of those advocating for patients. Yet these gains emerge out of historical contexts that sometimes involve health professionals but just as often owe their thanks to charismatic lay people with the vision, skills, and persistence to either agitate for change from the outside or gain entrée into the medical world and collaborate from that vantage point. These traditions of advocacy are instructive, both in terms of delineating core tenets held by patient advocates and in suggesting the need for "pitching a big tent" that embraces change agents from many backgrounds and professions.

Advocacy and the Helping Professions

The legal profession has put its own stamp on patient advocacy, particularly in the realm of establishing patient rights.³ In his commentary, Edward Connetta extends this discussion, offering a "then and now" snapshot of health care coverage and how he, as a practicing attorney, has worked to help people whose health benefit plans have denied coverage for life-saving medical treatment. As he reports, significant

gains have been made in this arena. Together with other reasons for these improvements, Connette cites “the development of a network of highly trained, non-attorney ‘patient navigators’ who typically come from nursing, medical claims processing, or insurance backgrounds.” As he puts it, “they perform miracles, and they do it quickly, usually at no cost to the patient.”

However the conversation does not stop with the law. As suggested by Connette, those in the helping professions of nursing and social work also have deep roots in patient advocacy,¹¹ as do those who offer particular kinds of care, such as mental health or palliative care, in which patients’ autonomy is frequently in jeopardy.¹²

Nurses in particular practice a form of patient advocacy within the health care system, often acting as a liaison between the patient and others involved with the provision of care. In this capacity, they mediate among family members, providers, medical institutions, insurance carriers, researchers, and others. Yet others take on this role as well, including social workers, physicians, and, increasingly, family members, lay health advisors, or hired patient advocates. Regardless of their professional affiliations, all those working as advocates in clinical environments are called to practice what Baldwin has identified as the three “essential attributes” of patient advocacy: (1) valuing patients’ rights to self-determination; (2) apprising patients through a combination of education and advising so that they may take full part in decision-making; and (3) interceding between patients and others, including family members and physicians, to ensure that patients’ wishes are honored.¹³

In their commentary on veterans seeking health care through the Veterans Health Administration (VHA), Linda Kinsinger, Joan Van Riper, and Kristy Straits-Tröster spotlight this role and, in doing so, underscore the way hospital-based patient advocates fill a critical need. If the advocates weren’t there, individual patients would suffer—critical information might not make it from one provider to another; a particular procedure might not be approved; or a patient might miss out on an opportunity to participate in a fully informed decision about his or her own treatment.

Yet as Lance Stell’s commentary on clinical ethics and patient advocacy suggests, intermediaries (in this case clinical ethicists) who work to protect patient autonomy can be compromised by institutional forces (the drive towards economy and efficiency within the workplace), by more personal forces (conflicts within families over the right course of treatment), or by the fact that advocates are not always in agreement themselves over which direction to go in. Furthermore, the ethical ideals imbued during advocates’ training (whether that training is in nursing, social work, philosophy, or some other discipline), while often stressing patient-centeredness as a core value, may attenuate under the immediacy of care delivery that necessitates pragmatic compromises. These challenges suggest the need on the part of hospital-based patient advocates or ethicists to maintain a delicate balance

between ethically representing the patient while also maintaining collegial relationships with hospital personnel to ensure that their requests get a fair hearing. In other words, the role of a patient advocate calls on the skills of the diplomat, the inquisitiveness of the educator and problem solver, and the courage of the activist to speak up in difficult situations.

Advocacy and Palliative Care

Patient advocacy also has roots in particular areas of health care delivery, such as palliative care. As with the nursing profession, advocates in palliative care have led in the effort to legitimize and increase 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.¹⁴ Their advocacy efforts have often focused on organizational change and, indeed, have resulted in hospice programs and health care powers of attorney designed to provide comprehensive services that safeguard patients’ wishes and guard their autonomy right up to the moment of death. In this model, physicians and nurses collaborate with families, religious and spiritual practitioners, volunteers, and others to minimize patients’ suffering and carry out patients’ wishes as they progress through this natural stage of life.¹⁵ Palliative care advocates’ success with this end-of-life care model illustrates ways in which advocates have helped redesign the organizational parameters of the health care system so patients’ rights and preferences are honored in all their complexities.

In this context, Laura Hanson’s commentary offers an update on disparities in how the palliative care model, as well as other forms of care, have been disseminated. As she points out, “African Americans are more than twice as likely as whites to make choices in favor of life-prolonging treatment,” meaning that they are less likely to access hospice care when treatment options are exhausted. Hanson’s piece underscores the degree to which the efforts of patient advocates have so far benefited some patients more than others. Yet Hanson also spotlights the work of advocates who are developing innovative ways to reach underserved populations. In her case, Hanson is testing the use of a lay health advisor model to identify African American cancer patients earlier in their illness, to involve them more fully in their care decisions, and to increase their awareness of palliative care options. Similarly, Carmen Lewis and Michael Pignone focus their advocacy efforts on health literacy, innovating ways to help *all* people grasp complex health information both out of respect for all patients’ right to agency and because activated, knowledgeable patients have better health outcomes than those who simply “follow doctors’ orders.”¹⁶ In their commentary, Lewis and Pignone discuss the use of decision aids as a means to increase informed decision-making in primary care.

Activism

A third realm of patient advocacy involves activists, often survivors of disease, who work to improve health care for people frequently marginalized by socially stigmatizing diseases,¹⁷ including HIV/AIDS or, in an earlier day, breast cancer. Patient advocacy in this context is often tied to broader social movements such as gay rights, women's rights, or consumer health movements. The activist tradition in advocacy spotlights the role of the "outsider," i.e., one who may not have been trained in the helping or legal professions but who can push for change based on charisma, strong organizing skills, and a lived experience of the issues at hand.¹⁸ The efforts of these "outsiders" in recent years have been fueled by new communication technologies like the internet that give patients and families unprecedented access to health information and the ability to share that information widely.¹⁹

In the case of breast cancer, patients, their family members, and survivors have helped change how clinicians, colleagues, and the public regard this once-stigmatizing disease.²⁰ Through their efforts, patient-provider communication is now more transparent, treatment guidelines have been modified, and employment laws have been changed.²¹ Advocates' public awareness campaigns, grassroots organizing, fundraising, lobbying, and coalition building have increased access to screening and treatment services; secured funding for discovery, translation, and dissemination; and introduced patients as experts in the process of designing and conducting breast cancer research.²² In this case, patients serve not just as the recipients of advocacy, but as the source of it as well.

In another stream of activism, many advocates focus on broader health issues relevant to minority populations. In her commentary, Florence Simán looks at health disparities among Latino immigrants living in North Carolina, directing attention to possible sources of misunderstanding between patients and providers once they have overcome considerable barriers blocking their access to care. Chloe Katz narrows that examination further in her discussion of the ways that refugee health issues may differ from those of other immigrants.

As the commentaries in this issue of the *North Carolina Medical Journal* suggest, other powerful dimensions of patient advocacy have also informed the movement. Yet nursing, palliative care, and disease-specific activism, together with the more recent focus on patient safety, can serve as a shorthand for the shared outlook and aims of this still nascent, but growing, social movement. More importantly, each of these traditions illustrate ideas central to patient advocacy: patients' right to self-determination; how changes in institutional culture can

better support people who are in need of care; how greater patient participation can increase patients' investment in their own health, deepening their trust in the provider along the way; and how an advocate's place inside or outside an organization affects the methods of advocacy she chooses and the degree of social change she achieves.

Patient Advocacy as a Profession?

Several scholars have identified signs that patient or health advocacy is coalescing as a profession.²³ They cite as evidence the initiation of several graduate level advocacy training programs^b and the proliferation of patient advocacy businesses such as Health Advocate, Inc.^c Additional indicators include recent calls for credentialing health advocates²³ as well as an increase in survivors of disease who work within hospitals as patient representatives, establish their own nonprofits, sit on review panels, and perform other important quality improvement work. This issue of *NCMJ* features some of these types of advocates, including Nancy Davenport-Ennis, the founder and CEO of the Patient Advocacy Foundation and the National Patient Advocacy Foundation and Tiffany Christensen, author of *Sick Girl Speaks*.

At UNC Chapel Hill, our training efforts have focused on methods of advocacy that health professionals can draw on—how health educators, hospital administrators, physicians, nurses, pharmacists, social workers, and occupational therapists can blend their advocacy skills and activist inclinations with their professional roles to powerful effect. We teach skills, such as media advocacy, as discussed by Ann Houston Staples in her commentary. We focus on ways to harness new media so that, as emphasized by Adam Searing in his commentary, advocates can be alert and ready when the time is ripe to make an all-out push for major reforms. And, as highlighted in the commentary by Joseph Colletti, we look closely at varying approaches for insuring more, if not all, US citizens. We focus on these strategies recognizing that, while patient advocacy may eventually come into its own as a profession with its own standards and tenets of training, those professionals who enter this arena without a distinct career track may need to be very entrepreneurial indeed. Yet as this issue of the *NCMJ* shows, these social entrepreneurs are one of *the* nerve centers of advocacy. Without their perspective and point of view, our advocacy efforts would be drained of the legitimacy provided by their lived experience.

Our understanding of patient advocacy concepts and core issues is still evolving, as is emphasized in the piece by Melissa

b Sarah Lawrence College (MA in Health Advocacy, est. 1980); University of Wisconsin (patient advocacy courses in law school for medical, nursing, and law students; Center for Patient Partnerships, est. 2000); University of Cincinnati (est. 2001); UNC at Chapel Hill (courses offered through the School of Public Health, est. 2006); and Columbia University (MA in Narrative Medicine, est. 2008).

c Health Advocate Inc. (<http://www.healthadvocate.com>) is a company that helps patients and family members navigate health care systems, from clinical to insurance issues. Personal health advocates, often registered nurses, help clients identify and secure appointments with the best doctors and hospitals for their particular conditions, help resolve insurance issues, help clients understand serious chronic conditions, and help clients and families identify additional health resources.

Gilkey and Jo Anne Earp. Each of the commentaries in this issue illuminates some aspect of patient advocacy in North Carolina, whether that means advocating for more thoughtful ways of working with immigrant or veteran populations, empowering patients with low literacy, or improving data collection and reporting methods to more easily identify and better track patterns of error in hospitals. By looking at these disparate issues through the lens of patient advocacy, we offer a better chance of working collectively to identify

advocacy strategies that can be effective in many settings to remedy some of the most stubborn problems in health care. Without health care quality improvement along the lines advocated in this issue of the *North Carolina Medical Journal*, we will not achieve the aims, scope, reach, or potential that the evolving patient advocacy social movement promises, not only to its adherents, but to patients and their families everywhere. **NCMJ**

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