

ARTICLE

The Evolution of Patient Advocacy: From Rights to Reality

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Abstract

Fifty years ago, George J. Annas and Joseph Healey introduced the concept of a “patient rights advocate” in their seminal 1974 article published in the *Vanderbilt Law Review*. Annas expanded this vision in the *ACLU Handbook, The Rights of Hospitalized Patients*, later broadening its scope to all medical settings. This essay traces the evolution of patient advocacy, highlighting pivotal milestones: the advent of cancer navigators, the rise of the patient safety movement, the establishment of patient advocacy organizations, the development of Patient Advocate Offices in hospitals, and the emergence of independent advocates with board certification. It also examines the impact of advocacy on healthcare outcomes, costs, and patient-provider satisfaction, and explores future directions for this vital and growing profession.

Keywords: Patient Advocacy; Patient Rights; Patient Centered Care; Informed Consent; Medical Ethics; Health Care Disparities

Dear Dad,

Something scary is happening. I’m lying on the bathroom floor; wedged between the tub and toilet. I’m not sure what time it is. I think it must be around midnight. I can’t move, Dad. What is going on? My hands are stone; aching, throbbing as if they will explode from the inside out. My fingers aren’t listening to my brain. My legs, Dad. My legs are gone. They’re not moving; limp, dead. What do I do, Dad? Help me!

*“Hey Siri! Call Anne!” Then I’m yelling to my phone. Where is it? Finally, it’s ringing. Message. F*ck. “Anne! Anne! Something bad is happening! Please pick up the phone!” I can feel tears streaming down my cheeks – hot and burning. What is going on? Choking, I yell, “Hey Siri! Call Harold!” I’m yelling to my phone. Where is it? Finally, it’s ringing. Message. F*ck. “Harold! Harold! Something bad is happening! Please pick up the phone!”*

What do I do, Dad? I can’t lie here. No one is here. I am alone, terrified. What if I die? Weeping, I beg for someone, something to wake me up from this nightmare. Surely, this can’t be real.

More useless attempts at contacting other family members. It’s very late. I think. How long have I been lying here? Hours, it seems. I keep waiting for something to switch; something that turns my body back on. Anything. Anything. Anything.

The dogs are worried. They keep licking my face. When I try to hold my hands up to push them away, they lick my hands. I mean, I see them lick my hands. Nothing, I feel nothing. My arms from my shoulders to wrists move independently. That has to be good, right, Dad?

Door opening. “Laura! Dan! I’m in the bathroom. Help!” I am shaking violently as emotions rip through me.

I can’t do this – whatever this is. I don’t want to be here. I can hear my anguished wails fill the room...

Christine O, a forty-six-year-old Autism Counselor, had been in her usual state of health until early June 2020, when she began to notice numbness and tingling in her hands. Later that month she had a mechanical fall and struggled to stand up due to profound lower extremity (LE) weakness. Her hand

numbness progressed to alternating burning pain and stark cold sensation. She went to Ascension Sacred Heart Health in Florida where her weakness was documented and a work-up revealed no clear cause for her symptoms. The night of July 10, Christine was found on the bathroom floor unable to move and was brought to the ER of Ascension Sacred Heart Health. After further work-up, she was given a diagnosis of Transverse Myelitis, treated with pulse dose steroids and intravenous immunoglobulin (IVIG) with minimal improvement. The hospital needed beds, so she was discharged to a rehab facility in the middle of the night after she was deemed “medically stable.” By this time Christine was functionally quadriplegic. She was not able to participate in any standard rehabilitation exercises. Her insurance was refusing to cover further rehab services and wanted her moved to a nursing home as soon as possible. This was the first summer of Covid-19 and Christine’s family in Massachusetts worried that shipping her off to a nursing home would seal her fate. They turned to a professional patient advocate for help. The advocate found major discrepancies in the records and shared the family’s concern that Christine did not receive a thorough diagnostic work-up and thus needed to be reevaluated by neurological specialists, ideally closer to family who could support her. The advocate had to:

- Delay any transfer to a lower-tier care nursing home and get the insurance to continue coverage of the rehab facility
- Overcome the resistance of the rehab physician who refused to discharge Christine back to an acute care facility
- Find an appropriate specialist at a Boston hospital willing to take her as a “direct admit”
- Figure out how best to arrange and pay for medical transport from a Florida rehab facility to a Massachusetts acute care hospital – all against the backdrop of Covid-19.

Introduction

The concept of patient rights advocacy has undergone significant transformation since its inception in the 1970s. George Annas and Joseph Healey’s seminal 1974 article, “The Patient Rights Advocate: Redefining the Doctor-Patient Relationship in the Hospital Context” was written while both were working at the Center for Law and Health Sciences of Boston University School of Law.¹ The authors laid the groundwork for this evolution by highlighting the need for a more balanced and patient-centered approach in health care settings.² This article traces the development of patient rights advocacy from its early days to the current state of patient and health care advocacy, emphasizing key milestones and contemporary practices.

Historical Context and Social Developments

The Civil Rights movement of the 1950s and 1960s set the stage for the emergence of patient rights advocacy. Following the 1954 Supreme Court decision in *Brown v. Board of Education* and the subsequent Civil Rights Act of 1964, there was a growing awareness of individual rights across various sectors of society.³

In this context, Ruth Ravich established the first Department of Patient Representation at Mount Sinai Hospital in New York in 1966.⁴ She later founded the Society for Healthcare Consumer Advocacy,

¹George J. Annas & Joseph M. Healey, Jr., *The Patient Rights Advocate: Redefining the Doctor-Patient Relationship in the Hospital Context*, 27 VAND. L. REV. 243, 243 (1974) (biographical notes).

²*Id.* at 245, 248–251, 266–68 (discussing balance of power between patients and doctors and patients and hospitals, and presenting model bill of patient rights).

³*Milestone Documents: Brown v. Board of Education (1954)*, NAT’L ARCHIVES, <https://www.archives.gov/milestone-documents/brown-v-board-of-education> [<https://perma.cc/5N2G-P9J7>]; *Milestone Documents: Civil Rights Act (1964)*, NAT’L ARCHIVES, <https://www.archives.gov/milestone-documents/civil-rights-act> [<https://perma.cc/G8ZV-NVED>].

⁴Interview by Albert S. Lyons & Florence Daniels with Ruth Ravich, in N.Y.C., N.Y. (Apr. 11, 1995) [hereinafter Interview with Ruth Ravich], https://archives.mssm.edu/aa107-int057;dacs?sf_culture=nl [<https://perma.cc/8CDN-TGFX>].

now part of the Beryl Institute, marking a significant step towards formalizing patient advocacy within health care institutions.⁵

The American Hospital Association adopted “A Patient’s Bill of Rights” in 1973, at a time when the traditional doctor-patient relationship was predominantly paternalistic, with doctors making decisions on behalf of patients who had little say in their own care.⁶ Annas and Healey argued that “as technology has increased the doctor’s ability to deal effectively with more health-threatening situations, it has also widened the gulf between doctor and patient... . The doctor’s position has been strengthened and the patient’s weakened.”⁷ They further suggest that imbalance was even more pronounced within the hospital setting: “The traditional model of the doctor-patient relationship creates serious problems in the hospital context that diminish the patient’s right of self-determination. Patients are unable to assert their rights in a hospital context because they are sick and remain passive because their main concern is the restoration of their health.”⁸ Growing public awareness of medical ethics issues, such as the Tuskegee syphilis study, brought the discussion of patient consent, self-determination, and ethical conduct in health care to the forefront.⁹ While Annas and Healey suggested there were models for the legal redefining of other relationships such as employer and employee, they concluded that “[t]he atmosphere of doctor dominance in the healthcare institution can be changed so that human rights are protected without affecting adversely the quality of care administered.”¹⁰ Emphasizing that statements about patient’s rights were neither self-enforcing nor guaranteed protection of the patient’s interests, Annas and Healey proposed the establishment of patient rights advocates to challenge conventional practice and ensure that patients’ voices were heard and their rights respected.¹¹ Key propositions from the article advanced the need for a comprehensive statement of patient rights,¹² the establishment of independent patient rights advocates,¹³ and the importance of informed consent and patient participation in medical decision-making.¹⁴

Their focus was primarily on hospitalized patients, and they deliberately chose the term “advocate” to describe someone called to assist, defend or aid.¹⁵ While they proposed that advocates should be loyal only to patients, they acknowledged the challenge of funding such roles, a foresight that plagues the field still.¹⁶

The first edition of Annas’ *The Rights of Hospital Patients* in 1975 also concentrated on inpatient encounters.¹⁷ In subsequent editions, the ACLU Handbook expanded its scope to include patients across all settings and changed its title to *The Rights of Patients*.¹⁸

⁵*Id.*

⁶PATIENT’S BILL OF RIGHTS (AM. HOSP. ASS’N 1973) (revised 1992), <https://www.americanpatient.org/american-hospital-association-patients-bill-of-rights/> [<https://perma.cc/9Q3F-XWW7>]; AM. HOSP. ASS’N, THE PATIENT

CARE PARTNERSHIP: UNDERSTANDING EXPECTATIONS, RIGHTS AND RESPONSIBILITIES (2003), <https://www.aha.org/other-resources/patient-care-partnership> [<https://perma.cc/V47B-G9G8>] (replacing the Bill of Rights with a plain language brochure).

⁷Annas & Healey, *supra* note 1, at 252.

⁸*Id.* at 269.

⁹Laura A. Barrett, *Tuskegee Syphilis Study of 1932-1973 and the Rise of Bioethics as Shown Through Government Documents and Actions*, 47 DOCUMENTS TO THE PEOPLE 11, 11–14 (2019).

¹⁰Annas & Healey, *supra* note 1, at 269.

¹¹*Id.* at 245.

¹²*Id.* at 264, 266–68.

¹³*Id.* at 257–58.

¹⁴*Id.* at 250, 263, 266–67.

¹⁵*Id.* at 258.

¹⁶*Id.* at 264.

¹⁷GEORGE J. ANNAS, THE RIGHTS OF HOSPITAL PATIENTS: THE BASIC ACLU GUIDE TO A HOSPITAL PATIENT’S RIGHTS (1975).

¹⁸GEORGE J. ANNAS, THE RIGHTS OF PATIENTS: THE BASIC ACLU GUIDE TO PATIENT RIGHTS (Humana Press, 2d ed. 1992) [hereinafter ANNAS, THE RIGHTS OF PATIENTS]. The guide is currently in its third edition, GEORGE J. ANNAS, THE RIGHTS OF PATIENTS: THE AUTHORITATIVE ACLU GUIDE TO THE RIGHTS OF PATIENTS (N.Y. Univ. Press, 3d ed. 2004).

Legislative and Institutional Developments

Following the publication of the Annas-Healey article, several legislative and institutional changes began to take shape. These changes aimed to formalize and protect patient rights within the health care system:

1. *Civil Rights and Institutionalized Persons Act (CRIPA) of 1980*: This Act authorized the U.S. Department of Justice to address the violation of rights for people in institutions, including mental health facilities.¹⁹
2. *Protection & Advocacy for Mentally Ill Individuals Act of 1986*: This act established a protection and advocacy system for persons with mental illnesses, requiring advocacy agencies to be independent of service delivery systems.²⁰
3. *Joint Commission on Accreditation of Healthcare Organizations (JCAHO)*: By the late 1980s, JCAHO began emphasizing patient rights, mandating systems for addressing patient complaints and informing patients about their rights.²¹

Historical Developments: Grassroots Efforts and Community Outreach

The concept of providing outreach and support to patients has deep roots in public health. Community Health Workers, dating back to the 1800s in Russia and popularized by China's 'barefoot doctors' in the 1920s, were early examples of patient advocacy.²² In 1975, the World Health Organization declared Community Health Workers essential to the success of health care, owing to their ability to address local conditions, which we now recognize as the social determinants of health.²³ More recent examples include "Street Doctor Programs," one of the first started by Dr. Jim O'Connell known as Boston Healthcare for the Homeless Program,²⁴ and the late Dr. Paul Farmer's concept of "accompaniment" in Partners in Health.²⁵

In addition to starting the Society for Healthcare Consumer Advocacy, Ruth Ravich later helped organize the first master's-level health advocacy program at Sarah Lawrence College in 1980, followed in suit by Assumption College.²⁶ Certificate programs in this space also emerged as options.²⁷ Ultimately, institutions of higher education play a fundamental role in developing and supporting professional preparation programs that are sorely needed to advance this unique skill set.

Dr. Harold Freeman's introduction of the first *patient navigator* program at Harlem Hospital in 1990 marked the beginning of the navigation movement.²⁸ The program aimed to eliminate barriers to timely

¹⁹Civil Rights and Institutionalized Persons Act (CRIPA) of 1980, 42 U.S.C. §§ 1997–1997j.

²⁰Protection & Advocacy for Mentally Ill Individuals (PAIMI) Act of 1986, 42 U.S.C. §§ 10801–10851.

²¹See ANNAS, THE RIGHTS OF PATIENTS, *supra* note 18, at 37–40 (discussing the patient's rights requirements of JHACO's 1989 accreditation manual for hospitals).

²²Shreya Kangovi et al., *From Rhetoric to Reality — Community Health Workers in Post-Reform U.S. Health Care*, 372 NEW ENG. J. MED. 2277, 2277 (2015).

²³*Id.*

²⁴*Our History*, BOSTON HEALTH CARE FOR THE HOMELESS PROGRAM, <https://www.bhchp.org/about/our-history/> [<https://perma.cc/8CZG-LTJB>] (last visited Sept. 26, 2024); see generally TRACY KIDDER, *ROUGH SLEEPERS* (2023); JAMES O'CONNELL, *STORIES FROM THE SHADOWS: REFLECTIONS OF A STREET DOCTOR* (2015).

²⁵IN THE COMPANY OF THE POOR: CONVERSATIONS WITH DR. PAUL FARMER AND FR. GUSTAVO GUTIÉRREZ 14 (Michael Griffin & Jennie Weiss Block eds., 2013); Wesler Lambert, *PIH Model for Accompaniment Informs Global Response to Shortage of Health Workers*, PARTNERS IN HEALTH (Apr. 1, 2007), <https://www.pih.org/article/pih-model-for-accompaniment-informs-global-response-to-shortage-of-hea> [<https://perma.cc/EN37-P9RX>] (last visited Sept. 26, 2024).

²⁶Interview with Ruth Ravich, *supra* note 4; *Health Advocacy Master's and Certificate Programs*, SARAH LAWRENCE COLL., <https://www.sarahlawrence.edu/health-advocacy> [<https://perma.cc/UP7W-WTTF>] (last visited Sept. 26, 2024).

²⁷See, e.g., PATIENT ADVOC. CERTIFICATION BD., <https://www.pacboard.org> [<https://perma.cc/G7BT-RHGE>] (last visited Sept. 15, 2024); *Public Health Advocacy Certificate Program*, JOHNS HOPKINS BLOOMBERG SCH. OF PUB. HEALTH, <https://publichealth.jhu.edu/academics/public-health-advocacy-certificate-program> [<https://perma.cc/K267-SUED>] (last visited Sept. 25, 2024).

²⁸Harold P. Freeman & Rian L. Rodriguez, *History and Principles of Patient Navigation*, 117 CANCER 3539, 3540 (2011).

care between suspicious findings, diagnosis, and treatment, particularly for underserved populations.²⁹ The results from the Harlem Breast Cancer Experience were dramatic. Before the intervention, only six percent were detected at Stage I.³⁰ After the intervention, that number rose to forty-one percent, contributing to a significantly improved five-year survival rate.³¹ Two major factors were believed to account for the dramatic improvement: free or low-cost breast examinations and screening, which led to early diagnosis, and patient navigation, which provided outreach, follow-up, and follow-through.³²

Based principally on the Harlem Patient Navigation Model, the *Patient Navigator and Chronic Disease Prevention Act* was passed by Congress in 2005 providing funding for patient navigation research.³³ In 2010, the Affordable Care Act required that states establish “navigator programs” as part of health insurance exchanges³⁴ and include case managers in patient-centered medical homes.³⁵ Though well intended, some case managers had over 300 patients to keep track of, making the goal of patient-centered care rather elusive.³⁶ In 2012, the American College of Surgeons Commission on Cancer mandated that hospital-based patient navigation become a standard of care for cancer programs starting in 2015.³⁷

Key Organizations: Supporting Patients and Promoting Safety

The non-profit Patient Advocate Foundation was established in 1996 to provide free case management services to patients needing assistance.³⁸ The same was true of the Pulse Center for Patient Safety Education and Advocacy.³⁹ Ilene Corinna had originally started the Pulse Center as a support group for survivors of medical error in the wake of her son’s tragic death, and it has since expanded to include courses teaching individuals how to advocate for themselves and others given the scope of unmet needs.⁴⁰

The 1999 publication of the Institute of Medicine’s (IOM) Report “To Err Is Human” was a significant turning point.⁴¹ Its assertion that at least 44,000, and perhaps as many as 98,000 deaths a year were

²⁹*Id.*

³⁰*Id.* at 3540–41.

³¹*Id.*

³²*Id.* at 3541. See also Harold P. Freeman, Barbara J. Muth & Jon F. Kerner, *Expanding Access to Cancer Screening and Clinical Follow-Up Among the Medically Underserved*, 3 CANCER PRAC. 19 (1995). A similar study aimed at decreasing colon cancer disparities by increasing screening rates in an inner-city population was recently done at New York’s Montefiore Einstein Comprehensive Cancer Center. As a sign of the times, the researchers employed an AI virtual patient navigator or conversational chat-bot called MyEleanor that provided the initial outreach to patients who either missed or canceled their colonoscopy appointments. Patient volume increased and completion rates for patients who did not show for initial appointment nearly doubled using the AI patient navigator tool to facilitate access and appointments. Alyson B. Moadel et al., *AI Virtual Patient Navigation to Promote Re-Engagement of U.S. Inner City Patients Nonadherent with Colonoscopy Appointments: A Quality Improvement Initiative*, 42 J. CLINICAL ONCOLOGY (2024 ASCO Annual Meeting I) 100 (2024).

³³42 U.S.C. § 256a.

³⁴42 U.S.C. § 18031(i); see also SUZANNE M. KIRCHHOFF, CONG. RSCH. SERV., R43243, HEALTH INSURANCE EXCHANGES: HEALTH INSURANCE “NAVIGATORS” AND IN-PERSON ASSISTANCE 4–7 (2014) (detailing navigator eligibility and application process).

³⁵42 U.S.C. § 256a-1.

³⁶Asia Friedman et al., *Facilitators and Barriers to Care Coordination in Patient-Centered Medical Homes (PCMHs) from Coordinators’ Perspectives*, 29 J. AM. BD. FAM. MED. 90, 93 (2016).

³⁷Harold P. Freeman, *The Origin, Evolution, and Principles of Patient Navigation*, 21 CANCER EPIDEMIOLOGY BIOMARKERS & PREVENTION 1614, 1615 (2012).

³⁸*Our History*, PATIENT ADVOC. FOUND., <https://www.patientadvocate.org/learn-about-us/our-history> [<https://perma.cc/TJB3-JCJS>] (last visited Sept. 26, 2024).

³⁹*About Us*, PULSE CTR. FOR PATIENT SAFETY EDUC. & ADVOC., <https://www.pulsecenterforpatientsafety.org/aboutus> [<https://perma.cc/J62Q-RXHD>] (last visited Sept. 25, 2024).

⁴⁰*Frequently Asked Questions*, PULSE CTR. FOR PATIENT SAFETY EDUC. & ADVOC., <https://www.pulsecenterforpatientsafety.org/faq> [<https://perma.cc/C6KU-ZS2C>] (last visited Oct. 3, 2024).

⁴¹See COMM. ON THE QUALITY OF HEALTH CARE IN AM., INST. OF MED., *TO ERR IS HUMAN: BUILDING A SAFER HEALTH SYSTEM* (Linda T. Kohn et al. eds., 2000) [hereinafter INST. OF MED., *TO ERR IS HUMAN*]; Debra Hardy Havens & Lizbet

attributable mostly to preventable medical errors⁴² had some of the greatest impact. The response from the industry was almost immediate; within a year, The Leapfrog Group was founded to collect, analyze, and publish data on safety and quality measures in health care, predicated on the IOM assertion: “[t]he problem is not bad people; the problem is that the system needs to be made safer.”⁴³

The term “medical error” also galvanized the relentless pursuit of patient advocacy from consumers, particularly in the wake of fundamentally preventable personal tragedies. The need to have an extra set of eyes and ears during interactions with health care providers — and ideally, the support of independent professionals to guide patients through the increasingly complex health care system — was clear to survivors and their families, who were motivated to spare others from similar grief. Based on her own experience with misdiagnosis, in 2009, Trisha Torrey started the Alliance of Professional Health Advocates (APHA) and AdvoConnection, which was a directory of independent health advocates.⁴⁴ In the same year, the National Association of Health Advocacy Consultants (NAHAC) was founded.⁴⁵ In 2010, Karen Curtiss started the Campaign Zero, now the Care Partner Project, after a series of preventable medical errors had led to her father’s death post-surgery.⁴⁶ Among other resources, Campaign Zero provides helpful checklists for patients to use before surgery, during emergencies, or prior to medical appointments.⁴⁷ HealthAdvocateX, another non-profit organization founded in 2012 in the Pacific Northwest, prioritizes community education in health care matters.⁴⁸ Following his near-death experience from undiagnosed sepsis, attorney L. Bradley Schwartz started the Greater National Advocates in 2018, which provides a free listing of independent advocates and their services.⁴⁹ Ultimately, four of these entities formed the Coalition of Health Care Advocacy Organizations (CHCAO) in 2022, functioning as an overarching policy arm.⁵⁰

Dear Dad,

Two very large male Marine nurses arrived in my room at the rehab to pick me up to fly home to Massachusetts today. I was loaded onto a stretcher, deposited into the ambulance, and driven to Pensacola Airport. Waiting there, you won’t believe this, Dad, a Lear Jet. It was sleek and kind of tiny. I wondered how in the world the nurses would fit into the jet. They were kind and funny as they loaded me in. I was strapped securely but if I craned my neck, I could see out the window. Nothing is working in my body. I was dressed in

Boroughs, “To Err Is Human”: A Report from the Institute of Medicine, J. PEDIATRIC HEALTH CARE, Mar./Apr. 2000, at 77, 77–80 (discussing 1999 publication of IOM report and immediate responses from Congress, president Clinton, and health organizations).

⁴²INST. OF MED., TO ERR IS HUMAN, *supra* note 41, at 1.

⁴³*About Us*, THE LEAPFROG GRP., <https://www.leapfroggroup.org/about> [<https://perma.cc/75VS-P82Z>] (last visited Sept. 25, 2024); INST. OF MED., TO ERR IS HUMAN, *supra* note 41, at 49; Lucian L. Leape & Donald M. Berwick, *Five Years After To Err Is Human: What Have We Learned?*, 293 JAMA 2384, 2385 (2005) (“The concept that bad systems, not bad people, lead to the majority of errors and injuries, which is a crucial scientific foundation for improvement of safety in all successful high-hazard industries, has become a mantra in health care.”)

⁴⁴*The History of the Alliance of Professional Health Advocates*, ALL. OF PRO. HEALTH ADVOCs. (Jan. 2022), <https://aphadvocates.org/about-apha/history> [<https://perma.cc/H87M-LEE7>]; *Trisha’s Misdiagnosis Story*, TRISHA TORREY, <https://trishatorrey.com/about/misdiagnosis/> [<https://perma.cc/6EJ2-SPJ3>] (last visited Oct. 24, 2024);

Find a Patient Advocate, UMBRA ADVOC. DIRECTORY, <https://app.umbrahealthadvocacy.com/search> [<https://perma.cc/2XTS-S4YE>] (last visited Sept. 25, 2024).

⁴⁵*About NAHAC*, NAT’L ASS’N OF HEALTHCARE ADVOC., <https://nahac.com/about-nahac> [<https://perma.cc/4HY9-B7JC>] (last visited Sept. 25, 2024).

⁴⁶*About Us*, THE CARE PARTNER PROJECT, <https://thecarepartnerproject.org/about/#Family-Story> [<https://perma.cc/24M7-EXYU>] (last visited Sept. 25, 2024).

⁴⁷*Hospital Care Checklists*, THE CARE PARTNER PROJECT, <https://thecarepartnerproject.org/hospital-stay-checklists> [<https://perma.cc/5538-5X38>] (last visited Sept. 26, 2024).

⁴⁸*Our Roots*, HEALTHADVOCATEX, <https://www.healthadvocatex.org/our-roots> [<https://perma.cc/B9KB-N85G>] (last visited Sept. 26, 2024).

⁴⁹*Patient Advocates: L. Bradley Schwartz*, GREATER NAT’L ADVOCs., <https://gnanow.org/advocates/bradley.html> [<https://perma.cc/7KZ8-S48R>] (last visited Sept. 26, 2024).

⁵⁰COAL. OF HEALTH CARE ADVOC. ORGS., <https://chcao.org> [<https://perma.cc/83PR-YZKN>] (last visited Sept. 26, 2024).

a johnny and wearing a freaking diaper and yet I was also lying there thinking that I was going home to family (and the best medical care) and, so silly of me, that this flight might be kind of cool.

Dad! I charmed (Ha!) one of the nurses into propping me up on my side so I could look out the window. I'm strapped in and propped up; yet I feel like a ragdoll. The view, Dad! Exquisite puffy clouds and, fortunately, blue skies. And the co-pilot is reading the newspaper. Hmmmmmm....

The flight home took around 2 hours. When I landed, Mom and Harold were there waiting for me. I was perplexed for a second then happy. Mom took out her phone for a photo of me. Glorious. Not a moment I want to preserve.

On July 31st, 2020, Christine was medically evacuated to the Brigham and Women's Hospital in Boston, Massachusetts for a second opinion. Her spinal imaging showed no clear cord disease, making a peripheral process more likely. A broad work-up was initiated. The advocate facilitated communication among various consulting specialists and made sure Christine understood the processes, reasons for requested diagnostic testing, and recommendations. The advocate also started working with the case manager regarding appropriate discharge planning.

Establishing the Profession of Patient and Health Care Advocacy

The key to establishing any new profession is the creation of a national standard-setting and certification body. Thus in 2012, a group of health care advocacy leaders came together and started the Patient Advocate Certification Board ("PACB").⁵¹ PACB's mission is to establish a standard of excellence in patient and health care advocacy through credentialing and setting standards, with a vision of achieving board certification for all advocates.⁵² As the examination process took shape, the PACB introduced pathways to certification based on both education and experience— an approach first advocated by Healey and Annas in 1974.⁵³

Despite some overlap with other groups, the PACB founders argue that the knowledge, skills, and abilities unique to patient and health care advocacy justify distinct domains of practice, a dedicated certification, specialized continuing education requirements, and a specific Code of Ethics.⁵⁴ A formal Job Task Analysis Study was completed and published in 2024, affirming five core domains of practice: Scope of Practice; Empowerment, Autonomy, Rights, and Equity; Communication and Interpersonal Relationships; Health, Medicine, and the Healthcare System; and Professionalism and Ethics.⁵⁵ With two exam periods per year, the PACB has certified over 1300 advocates since 2018.⁵⁶

The Affirmation included in the Code of Ethics for Patient and Health Care Advocates draws on the goals of the 2001 IOM report *Crossing the Quality Chasm*, namely to strive for "healthcare that is safe, effective, patient-centered, timely, efficient, and equitable."⁵⁷ The Code also uses a broad definition of advocate to include professional "health and health care advocates, patient advocates, patient navigators, health or patient advisers, care managers, and case managers, as well as those who work on behalf of communities, consumers, and family caregivers (including advocacy on legislative and health policy

⁵¹See PATIENT ADVOC. CERTIFICATION BD., *supra* note 27.

⁵²*About Us*, PATIENT ADVOC. CERTIFICATION BD., <https://www.pacboard.org/about> [<https://perma.cc/L373-A6P3>] (last visited Sept. 25, 2024).

⁵³See Annas & Healey, *supra* note 1, at 264.

⁵⁴*Ethical Standards: Code of Ethics for Board Certified Patient Advocate*, PATIENT ADVOC. CERTIFICATION BD., <https://www.pacboard.org/ethical-standards/> [<https://perma.cc/2X3G-L4ZR>] (last visited Sept. 25, 2024).

⁵⁵*Competencies and Best Practices*, PATIENT ADVOC. CERTIFICATION BD., <https://www.pacboard.org/competencies/> [<https://perma.cc/D5MX-QDV2>] (last visited Sept. 25, 2024).

⁵⁶*BCPA Certificant List*, PATIENT ADVOC. CERTIFICATION BD., <https://www.pacboard.org/bcpa-certificant-list/> [<https://perma.cc/MP2S-QVSG>] (last visited Oct. 24, 2024).

⁵⁷*Compare NAT'L ASS'N OF HEALTHCARE ADVOC., CODE OF ETHICS FOR PATIENT AND HEALTH CARE ADVOC.* 3 (2022), <https://chcao.org/wp-content/uploads/2022/06/20220607-COE-Published-compressed-1.pdf> [<https://perma.cc/X78R-W9G8>], *with INST. OF MED., TO ERR IS HUMAN*, *supra* note 41, at 197.

initiatives). [These] [a]dvocates may work independently, in a medical setting, or on behalf of communities or disease-specific populations across organizations and agencies.”⁵⁸

The Code of Ethics for Patient and Health Care Advocates does not specifically mention the pharmaceutical industry medication access specialists or clinical trial facilitators, both of whom are considered patient advocates. Similarly, while most hospitals now have the so-called “patient advocate” or “patient experience offices,” it is important to recognize that they function more as a blend of risk management and public relations within their organizations.

Thus, while many professionals refer to themselves as advocates, Annas and Healey’s proposition of a person “*whose primary responsibility and loyalty are commanded by the patient alone...*”⁵⁹ and who shall “*assist you in all the decisions you must make and in all situations in which your health and welfare are at stake*”⁶⁰ is currently only fulfilled by independent patient and health care advocates. Their allegiance is purely to the patient – or more accurately, to the client.⁶¹

The Scope of Practice for Independent Patient and Health Care Advocates

The scope of practice for independent health care advocates is much broader and more critical than originally envisioned. The advocate serves as a liaison between patients, health care professionals, and the extended care team, ensuring that patients’ rights are respected and their voices heard. The following are key areas where patient and health care advocates can make a significant impact:

1. Ensuring Informed Consent

Patients have the right to understand their medical conditions and proposed treatments. Advocates can help ensure that patients receive clear, comprehensive information about their diagnosis, treatment options, risks, and benefits.⁶² This is particularly important in the context of complex medical procedures and experimental interventions.

2. Protecting Privacy and Data Security

With the increasing use of digital health technologies and AI, protecting patient privacy and data security is paramount. Advocates can help patients understand their rights under laws such as HIPAA and ensure that health care providers comply with these regulations.⁶³

3. Navigating Regulatory Complexities

The health care regulatory landscape is continually evolving. Advocates can assist patients in understanding how new regulations, such as those affecting reproductive health post-*Dobbs*, impact their care. They can also help health care professionals navigate these changes to ensure compliance and protect patient rights.⁶⁴

⁵⁸NAT’L ASS’N OF HEALTHCARE ADVOC., *supra* note 57, at 7.

⁵⁹Annas & Healey, *supra* note 1, at 263.

⁶⁰*Id.* at 266.

⁶¹See Bos. Univ. Sch. of Pub. Health, *Annual Cathy Shine Lecture Featuring Heidi B. Kummer: The Case for Patient and Health Care Advocates*, YouTube, at 16:18–16:33, 25:58–26:54 (Apr. 5, 2023), https://www.youtube.com/watch?v=Aa_Es85Gi84&t=2s [https://perma.cc/224J-UL7A].

⁶²See Linda Keslar, *The Evolution of the Doctor-Patient Relationship*, MED. ECON. J., Oct. 2023, at 84, 88–89.

⁶³See Lisa Amanti et al., *Top Ten Issues in Health Law 2024*, AM. HEALTH L. ASS’N (Jan. 1, 2024), <https://www.americanhealthlaw.org/content-library/connections-magazine/article/d91b2697-e96b-49e4-84c1-1b8399406f5e/top-ten-issues-in-health-law> [https://perma.cc/FT8K-M2DF] (discussing “Health Care’s AI Transformation” in § 1).

⁶⁴See *id.* (discussing the state of reproductive health in 2024 in § 6).

4. Addressing Health Care Disparities

Advocates can play a crucial role in addressing health care disparities by ensuring that all patients receive equitable care regardless of their background. This includes advocating for patients who may face language barriers, financial constraints, or other obstacles to accessing quality health care.⁶⁵

Although many independent advocates come from health care-related fields or have clinical backgrounds, they do not give medical advice or perform medical procedures or functions, even if they hold clinical licenses. Many independent health care advocates choose to specialize in issues such as cancer, mental health, solo aging, billing, or insurance. With the ever-changing landscape surrounding reproductive health and end-of-life choices, the demand for birth and death doulas is growing.

The Concept of “Shared Decision-Making”: A Balancing Act

Medical paternalism continues to pose challenges for quality metrics and patient experience, yet patient autonomy, when taken to extremes, can present its issues. In the United States, patient autonomy rules. While most believe medical knowledge and experience should play a significant role in informed decision-making, physicians often provide insufficient input, prioritizing the patient’s wishes and “decision-making responsibility” over their own professional guidance. When a physician, unwilling to give advice on evidence-based practices or standards of care, simply presents options and expects the patient to “pick” a preference, they are not avoiding liability but rather abandon their duty “to care.” The ideal goal should be *informed decision-making*, which takes time and requires active listening and information-sharing from both sides: the health care professional, who brings medical expertise, and the patient, who brings knowledge of themselves, their goals, and their values. In today’s health care system, reimbursement and billing mechanisms generally preclude such crucial conversations.⁶⁶ Equally troubling is that most health care professionals lack the time for genuine collaboration with interdisciplinary providers, let alone with the patient and their families.⁶⁷ By promoting patient engagement and empowerment, advocates help patients take an active role in health care decisions by educating them about their rights, preparing them for medical appointments, and supporting informed decision-making.

A recent survey by the Coalition of Health Care Advocacy Organizations and The Advocate found that working with an advocate enhances understanding, leading to more realistic expectations and better shared decision-making.⁶⁸ Over ninety-five percent of respondents believed every patient should have access to an advocate.⁶⁹ Over eighty percent reported feeling more empowered and successful in navigating care and had greater confidence in decision-making.⁷⁰ Providers stated that having advocates as part of a patient’s care team also reduced the burden on the medical staff.⁷¹

Current Trends and Challenges: Navigating a Changing Landscape

The COVID-19 pandemic has reignited interest in patient and health care advocacy due to setbacks in patient safety and health care equity. Advocates play a crucial role in addressing health care disparities by

⁶⁵See Ana Natale-Pereira et al., *The Role of Patient Navigators in Eliminating Health Disparities*, 117 *CANCER* 3543, 3549–51 (2011).

⁶⁶See Ann S. O’Malley et al., *Policy Options to Encourage Patient-Physician Shared Decision Making* 5 (Nat’l Inst. for Health Care Reform, Pol’y Analysis No. 5, 2011).

⁶⁷See Tanner J. Caverly & Rodney A. Hayward, *Dealing with the Lack of Time for Detailed Shared Decision-Making in Primary Care: Everyday Shared Decision-Making*, 35 *J. GEN. INTERNAL MED.* 3045, 3045 (2020).

⁶⁸LEA CHRISTO ET AL., *COAL. OF HEALTH CARE ADVOC. ORGS., THE CRITICAL ROLE OF PATIENT AND HEALTH CARE ADVOCATES: A SPECIAL REPORT* 1, 8 (2023), <https://chcao.org/special-report-2023/> [<https://perma.cc/5KUL-CK7T>].

⁶⁹*Id.* at 9.

⁷⁰*Id.* at 10.

⁷¹*Id.* at 12.

ensuring that all patients receive equitable care regardless of their background. This includes advocating for patients facing language barriers, financial constraints, or other obstacles to accessing quality health care.

While technology has improved diagnostic and treatment capabilities, it has also introduced complexities in data privacy and security. The integration of artificial intelligence (AI) in health care presents both opportunities and risks that need careful management and vigilance. Recent legal developments and the post-*Dobbs* landscape affecting reproductive health have added to the challenges of day-to-day access to care.⁷² Patient and health care advocates can play a crucial role in helping patients understand evolving state-by-state regulations, ensuring patients are informed about the legal restrictions and their medical options, particularly in states with stricter abortion laws. This is especially vital for patients who face additional barriers, such as financial constraints or limited access to accurate information. With their sole allegiance to the clients, independent patient advocates are uniquely qualified to identify available care and treatment options that are safe and compliant, while facilitating equitable access to services and protecting patient rights.

Such assistance has been made easier by telehealth and virtual appointments, allowing independent advocates to assist clients nationwide and increase access to patient and health care advocacy services for individuals in underserved areas.⁷³ Employer benefits plans are increasingly contracting with health advocacy companies, offering personalized navigation services.⁷⁴ Students at Boston University and Rice University have started programs to educate undergraduates in understanding health care terminology and access, promoting self-advocacy.⁷⁵

The idea of patient rights advocates proposed by Annas and Healey fifty years ago has evolved considerably. Hospitals now have “patient advocate” or “patient experience offices.” In-patient cancer navigators become a part of the standard of care, and Medicare has added reimbursement codes for out-patient cancer and principal illness navigation services. Employer benefits plans are increasingly contracting with health advocacy companies that offer personalized navigation services, especially as they recognize that well-informed employees receive better, more targeted care, which, in turn, reduces resource utilization and costs.⁷⁶

Challenges remain, including issues of nomenclature and allegiance, awareness of professional patient advocates, availability of training opportunities, and established payment models for advocacy services. While many advocates are employed by hospitals, pharmaceutical companies, or employee assistance programs, most independent advocates are paid out-of-pocket by clients or their families.⁷⁷ Non-profit organizations offer pro bono services, and in states with Medicaid expansion, Community Health Worker

⁷²Aziza Ahmed et al., *Dobbs v. Jackson Women’s Health: Undermining Public Health, Facilitating Reproductive Coercion*, 51 J.L. MED. & ETHICS 485, 485, 487–88 (2023); Susan Frelich Appleton & Laura A. Rosenbury, *Reflections on “Personal Responsibility” After COVID and Dobbs: Doubling Down on Privacy*, 72 WASH. U. J.L. & POL’Y 129, 132 (2023).

⁷³MEDICARE LEARNING NETWORK, CTR. FOR MEDICARE & MEDICAID SERVS., MLN901705, MLN FACT SHEET: TELEHEALTH SERVICES 3 (2024), <https://www.cms.gov/files/document/mln901705-telehealth-services.pdf> [<https://perma.cc/27BA-55SS>].

⁷⁴See, e.g., *Health Advocacy & Navigation*, HEALTH ADVOC., <https://www.healthadvocate.com/site/product-index/health-navigation> [<https://perma.cc/9BUN-32LD>] (last visited Sept. 24, 2024).

⁷⁵Our Team, HEALTHPAIR, <https://healthpair.org/our-team> [<https://perma.cc/Z7QW-JMF9>] (last visited Sept. 24, 2024); Avery Ruxer Franklin, ‘Knowledge Is Power’: Rice Students Create Startup to Help People Take Control of Their Health Care, RICE NEWS (June 13, 2024), <https://news.rice.edu/news/2024/knowledge-power-rice-students-create-startup-help-people-take-control-their-health-care>; THE HEALTHCARE NAVIGATOR, <https://www.thehealthcarenav.com/> [<https://perma.cc/VK9S-BXAF>] (last visited Sept. 24, 2024).

⁷⁶*Impact of Implementing Personalized Advocacy*, ACCOLADE, <https://www.accolade.com/resources/one-sheet-aon/> [<https://perma.cc/94J2-A8L3>] (last visited Sept. 25, 2024).

⁷⁷*An Overview of the Profession of Health and Patient Advocacy*, ALL. OF PRO. HEALTH ADVOC., <https://aphadvocates.org/profession-overview/> [<https://perma.cc/G9KM-4YYM>] (last visited Sept. 25, 2024); *What Does It Cost to Hire a Patient Advocate?*, UMBRA HEALTH ADVOC., <https://umbrahealthadvocacy.com/what-does-it-cost-to-hire-a-patient-advocate/> [<https://perma.cc/87Q5-RY4J>] (last visited Sept. 25, 2024).

services are covered.⁷⁸ Additionally, Medicare published four new “incident to” codes allowing providers to be reimbursed for ordering and supervising outpatient Principal Illness Navigation (PIN) services.⁷⁹

Dear Dad,

There is a beautiful, luminous rolling bubble just inches from my grasp. No matter how I stretch, no matter how I cry and moan and yell and push, I cannot reach it.

The bubbles flow by like reels of film and vibrate. I see my house in Pensacola, my cats, my pool, my peace. I feel the sun. I see my friends, clients, and families that I’ve worked with and grown with over the years. I can see it all. I can feel it all there in its’ technicolor brightness. Images roll and fade, appear and disappear. Each next image disappears down into a sucking, gasping hole that takes a piece of me with it. There’s nothing left.

*But Dad – I’m lying here in the hospital bed. I can’t move my legs. I’m wearing a diaper. My hands are useless. I’m scared. I’m alone. I’m angry and I wish I was anywhere except alive. I’m exhausted from trying and it’s all just the beginning without an end in sight. I like endings. Tasks completed. To-do lists checked off. This f*cking disease has no end. Transferring from the bed to the chair aids almost dropping me. Slide boards, Hoyer lift. Students always watching. I decided to learn how to feed myself one day and ended up with food all over the place; It was macaroni and cheese for lunch. Such a waste of good food!*

After a thorough evaluation, Christine’s diagnosis was changed to Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) and she started with appropriate treatments. She continued to need assistance with all self-care activities, as she was unable to stand or walk. Thanks to the advocate’s intervention, Christine was transferred to Spaulding Rehabilitation Hospital in Charlestown on August 12, 2020, for intensive physical therapy to maximize her chances of functional recovery. There, the advocate worked with the care team and case manager to arrange the Social Security Disability Insurance (SSDI) application, secure necessary home equipment, coordinate personal care attendants, and facilitate communication among various health care professionals and family members involved in Christine’s recovery.

Future Outlook

A recent global survey of patient advocacy solutions projects an annual growth rate of nearly eleven percent for the market worldwide.⁸⁰ The United States Bureau of Labor Statistics also predicts a thirteen percent growth in all health care careers between 2021 and 2031, driven by increased demand for health care services from the Baby Boomer generation.⁸¹ Currently, patient and health care advocates are classified under the standard occupational code for “Patient Representatives.”⁸² In response, leaders from major health care advocacy organizations are working to establish a distinct code that accurately reflects advocates’ scope of work. Additional efforts include expanding health advocacy curricula and training programs across the country to help grow the profession, improve access, and ensure that competently trained advocates are available to meet the growing demand for services.

⁷⁸Natalie Lawson, *Momentum for Community Health Workers in Medicaid Continues in the New Year*, GEO. UNIV. McCOURT SCH. OF PUB. POL’Y CTR. FOR CHILD. & FAMS. (Jan. 29, 2024), <https://ccf.georgetown.edu/2024/01/29/momentum-for-community-health-workers-in-medicare-continues-in-the-new-year/> [<https://perma.cc/B7HX-HDDZ>].

⁷⁹CMS Creates New Codes to Reimburse for Navigation Services, AVALERE (Mar. 11, 2024), <https://avalere.com/insights/cms-creates-new-codes-to-reimburse-for-navigation-services> [<https://perma.cc/7PDM-PQT5>]. *Health Equity Services in the 2024 Physician Fee Schedule Final Rule*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/files/document/mln9201074-health-equity-services-2024-physician-fee-schedule-final-rule.pdf-0>.

⁸⁰INFINITY BUS. INSIGHTS, *GLOBAL PATIENT ADVOCACY SOLUTIONS MARKET – INDUSTRY STATUS AND PROSPECTS PROFESSIONAL MARKET RESEARCH REPORT 2024-2032* (2024).

⁸¹Emily Krutsch & Javier Colato, *World Health Day: Celebrating Good Health and In-Demand Healthcare Jobs*, U.S. DEP’T OF LAB. BLOG (Apr. 5, 2023), <https://blog.dol.gov/2023/04/05/world-health-day-celebrating-good-health-and-in-demand-healthcare-jobs> [<https://perma.cc/52ND-HZSB>].

⁸²See Emp. & Training Admin., U.S. Dept. of Lab., *Patient Representatives — 29-2099.08*, O*NET ONLINE, <https://www.onetonline.org/link/summary/29-2099.08> [<https://perma.cc/9VT8-VJWZ>] (last visited Sept. 25, 2024).

First steps. I walked 12 steps today. Doing stairs. Peter Pan

Thanks to Christine's incredible perseverance and hard work, she made a remarkable recovery from being functionally quadriplegic to walking, driving, and once again living fully independently. There is no doubt that her outcome would have been a very different one had her family not intervened and worked with a professional patient advocate.

Conclusion

Since the seminal work of Annas and Healey at Boston University, patient rights advocacy has achieved significant milestones, though it still faces challenges that require persistent efforts and innovation. By tracing the development of patient rights advocacy from its inception to today, we can appreciate the progress made while recognizing the continued need for dedicated patient and health care advocates. These advocates play a crucial role in ensuring that patients' voices are heard and safeguarding their rights, contributing to a more equitable and effective health care system.

In the complex landscape of 21st-century health care, the role of patient and health care advocates remains essential. Specialization in advocacy fosters mutual trust, improves patient outcomes, and ensures that all patients receive the care they deserve. The evolution of patient rights advocacy from concept to practice highlights the significant achievements and the moral imperative to address current and future challenges in promoting patient-centered care.

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