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History And Trends In The Field Of Healthcare Advocacy

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BY ELISABETH SCHULER, BCPA, CSA,
FOUNDER AND CEO, PATIENT NAVIGATOR, LLC

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HISTORY AND TRENDS

IN THE FIELD OF HEALTHCARE ADVOCACY

"I wish I had known you when …" is how folks generally respond when I tell them that I am a patient advocate and my job is to help patients and families navigate through our healthcare system. They tell me stories about when they were overwhelmed, confused, afraid, or unsatisfied by our complicated, expensive, and often inefficient healthcare system in the United States: an aging parent receiving inadequate care, an unsuccessful emergency room visit, a new and frightening diagnosis, battles with their insurance company, the specialist merry-go-round, or dismissive doctors.

The idea that patients need support from family members or friends to help them through a crisis is not new. However, private patient and healthcare advocacy as a separate profession has gained attention in the past twelve years because it fills so many gaps in the current American healthcare system. This profession, born of necessity and nurtured by its trailblazers, now plays an integral role in helping patients and families achieve better health outcomes, save money, and reduce stress during difficult medical journeys.

Separately, some hospitals now hire clinically trained patient navigators. For example, hospital-based breast cancer navigators help patients with the administrative management of their illness within their hospital system. In the past decade, private advocates have created professional organizations to represent us, established codes of ethics, competencies and best practices, built a national credential to certify advocates, and developed directories to find and hire a private advocate. Patients can now seek out competent, compassionate advocates to guide them toward better outcomes and teach them to become their own best advocates.

What is the history of healthcare advocacy and patient navigation?

The concept of patient and healthcare advocacy in the United States gained significant attention as part of the movement for patient rights in the 1970s. The Society for Healthcare Consumer Advocacy and the first Patient Representative Department at Mount Sinai Hospital in New York were created by Ruth Ravich in 1967. In 1972, the American Hospital Association (AHA) incorporated a patient bill of rights into the accreditation standards for hospitals (AHA, 1972).

Sarah Lawrence College in New York established a master's degree program in Health Advocacy in 1980 to educate professionals to work in hospitals, community, or private settings.

While hospitals began to recognize patient rights in the 1970s and 80s, the concept of "patient navigation" was founded in 1990 by Harold P. Freeman, a surgical oncologist at Harlem Hospital, for the purpose of eliminating barriers to timely cancer screening, diagnosis, treatment, and supportive care. His program has since evolved to include the movement of an individual across the entire healthcare continuum from prevention, detection, diagnosis, and treatment to end-of-life care. As empirical evidence accrued to support his findings (Freeman, 2012), U.S. policymakers came together to support the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (Public Law 109-18). The Act authorized $25 million over five years to develop community-based navigation programs. The Center to Reduce Cancer Health Disparities was created at the National Institutes of Health. Data from Dr. Freeman's programs began to prove how valuable navigation could be to improve cancer diagnosis and treatment outcomes. These types of positive outcomes have given rise to other community-based navigator efforts.

At about the same time, other organizations were founded to help patients improve health or aging outcomes. Members of the Aging Life Care Association (formerly known as Geriatric Care Managers and formed in 1985) are health and human services specialists who act as a guides and advocates for families who are caring for older relatives or disabled adults. The Patient Advocate Foundation (PAF), founded in 1996, is a national 501(c)(3) non-profit organization that provides case management services and financial aid to Americans with chronic, life-threatening, and debilitating illnesses. Many national advocacy groups now offer help navigating the diseases they represent, such as breast cancer or Alzheimer's disease.

It's no wonder that there is confusion about these definitions of who is an advocate or navigator, what they do, and who pays them. The evolution of navigation and advocacy has now grown to cover almost anything being done to help patients and families find their way through the maze of our healthcare system.

What are private patient advocates?

Even as the U.S. government began to address the disparities in access to cancer care among specific communities and populations in the past sixteen years, the idea of private, one-to-one patient and healthcare advocacy was born of necessity as a way to mitigate the complicated, inefficient, expensive, and fragmented healthcare delivery system. Just as many people now use a financial advisor, legal advisor, or life coach to manage different areas of their lives, Americans are learning that they can likewise hire a private healthcare advocate with insider knowledge and direct experience about how the healthcare system works. These healthcare system advisors work to improve medical outcomes, overcome obstacles in the healthcare system, and find resources in the same way that other expert advisors solve problems and avoid pitfalls in their professional arenas.

What kinds of things do private patient and healthcare advocates do?

Private patient advocates work directly for, and are paid by, individuals and families. Their only allegiance is to those individuals. Private advocacy services are not generally covered by insurance. We work with our clients and families to help them at many points along the healthcare continuum, including:

- disease research,
- insurance problems,
- finding doctors,
- understanding treatment and care options,
- preparing for and accompanying them to visits,
- serving as coach and quarterback of their healthcare team,
- facilitating communication with family members, caregivers, and doctors,
- mobilizing resources,
- managing medical paperwork,
- guiding them through aging parent transitions,
- gathering and deciphering medical records,
- serving at the hospital bedside, or
- simply offering a soft shoulder to cry on.

Many advocates do most of these things, but there is no single business model or list of services. Some advocates might only work with older adults, cancer patients, or medical billing and insurance problems. It depends entirely on the advocate's business and practice.

Who are private patient advocates and hospital-based patient navigators?

Early on, it was often nurses or social workers who started healthcare advocacy practices. Physicians are also starting advocacy businesses after having worked within the healthcare system. Additionally, advocates may come to this work because they have been through a life-changing medical event — either themselves, or with a friend or loved one. They have learned the hard way how difficult it can be to navigate and manage a complicated diagnosis, treatment, or chronic condition. They experienced the confusion, lack of coordination, dangers, and inefficiencies in our healthcare delivery system and now they want to share both what they have learned and how to avoid missteps along the way. Some advocates are laypeople with no prior medical experience or training who come from a variety of backgrounds. Health and patient advocates are often independent, working in private practice (their own businesses) for one or more patients at a time. Each handles his or her work differently.

Some people wonder what the distinction is between private patient healthcare advocates and hospital-based patient navigators. Typically, the primary focus of hospital-based navigators (such as breast cancer navigators) is to make sure that the doctor's instructions, prescriptions, tests, and discharge orders are carried out while the patient is in treatment within the facility or hospital system that employs them. The goal is to successfully "navigate" a patient **within** that institution.

Independent, private advocates, on the other hand, only work on behalf of their clients and guide them through their medical journey and transitions of care, such as seeking out other doctors and institutions, researching treatment options, and staying with the client after discharge to the home. An advocate, when contacted by a newly diagnosed patient, might begin with, "Let's get a second opinion from an independent source." Private advocates should be able to provide credible research so that the patient, with his or her medical team, can make informed decisions and connect with community resources. However, an advocate must never make decisions for the client, cross the line into doing clinical work, or offer a diagnosis. According to our advocate code of ethics, even medically trained advocates must focus solely on representing and advocating for their clients, not practicing medicine.

How is this profession organized?

As with any new profession, it has been a process of building, growing, and professionalizing over the past ten-plus years. Advocate leaders realized early on that it was important to establish a professional organization and a code of ethics. In August 2009, the National Association of Healthcare Advocacy Consultants (NAHAC, now named the National Association of Healthcare Advocacy), was established by Joanna Smith, (LCSW, MPH), the owner of Healthcare Liaison in Berkeley, California. Founding members of NAHAC believed that individuals working as advocates needed to come together to create guidelines for this profession and to educate consumers about its existence and usefulness. Today, NAHAC is a non-profit organization dedicated to improving patient outcomes through the promotion of the profession of healthcare advocacy through empowerment, education, and collaboration. NAHAC developed the first code of ethics and best practices for this profession, which have served as models for others.

Also in 2009, Trisha Torrey founded AdvoConnection, originally a national directory to help patients find advocates. In 2012, this directory grew into the Alliance of Professional Health Advocates (APHA), an extensive professional and support organization for private, independent patient advocates. The Alliance focuses on the business side of advocacy. Its goal is to help advocates start and grow successful practices, and to help them improve patient outcomes by maximizing their reach.

In January 2012, a group of individuals representing various advocacy constituencies came together with the goal of creating a substantive, accredited national patient advocacy credential. That effort led to creation of the non-profit Patient Advocate Certification Board (PACB).

The most recent organization created with the mission of transforming people into active participants in their care is Health AdvocateX, which grew out of the Washington State Health Advocacy Association (WASHAA) founded by Beth Droppert (BSN, RN) and Robin Shapiro in 2012. Health AdvocateX is a national, nonprofit organization that brings together health advocates, patients, caregivers, health providers, allied health businesses, communities, and educational representatives to promote health advocacy with the purpose of helping every person get the care they deserve.

What qualifications should an advocate have?

To tackle the issue of setting standards and competencies and to promote excellence in patient and healthcare advocacy, the Patient Advocate Certification Board (PACB) worked for six years to develop the Board Certified Patient Advocate (BCPA) credential. The PACB is set up to:

- manage and maintain a universally recognized certification for patient and health advocates;
- establish and maintain relevant knowledge domains, skills, ethical standards, and best practices for advocates;

- collaborate with healthcare consumers to achieve patient and family centered care;
- establish professional development for certified advocates; and
- promote and professionalize patient advocacy.

The certification examination to become a Board Certified Patient Advocate (BCPA) is now given to qualifying candidates twice a year. The first cohort of BCPA candidates was credentialed in March 2018. As of summer 2021, PACB has credentialed 889 advocates.

Currently, there is no mandatory education, experience, or qualification for a private patient or healthcare advocate. It is not yet a profession that requires licensure. Choosing an advocate with his/her Board Certified Patient Advocate credential, however, offers a competency level tested by an independent third party; accountability through ethical standards and/or a disciplinary process; and recertification requirements for continued learning and enhanced competence. Membership in a professional advocacy organization is also desirable. Since 2005, other courses, certificate programs, and university programs have been developed to educate patient advocates to work in a variety of settings (Master List — 2021).

How can I find a healthcare or patient advocate?

Consumers now have several ways to find and screen healthcare advocates. AdvoConnection offers a searchable directory of members on its website, as do the National Association of Healthcare Advocacy (NAHAC), the Patient Advocate Certification Board (PACB), HealthAdvocateX, and Greater National Advocates (GNA). Word of mouth or personal referrals are always a good way to find an advocate as well.

What questions should I ask if I want to hire someone? What should I expect? What do they charge?

You should interview an advocate the same way you would interview any other professional you would consider hiring. Among questions you could ask are:

- Have you handled other cases similar to mine before?
- What is your background and training?
- How long will it take to perform the services I need?
- What do you charge?
- Do you have client references I may contact?
- Do you provide written reports?
- Where are you located?
- What are your hours?
- How do you communicate with your clients?
- What would you typically do to help someone in my situation?

Working with a patient advocate is an intensely personal relationship. You must feel that you can trust and work with that person comfortably. You should expect that the advocate will respect your privacy and cultural preferences and that he or she is a good communicator. You may need to speak with several candidates before you feel comfortable hiring one.

You should also expect a written contract or agreement which specifies what the advocate will deliver to you and when, as well as a detailed explanation of his or her fees and charges. Do not rely on verbal promises or commitments; get it in writing. There is no standard fee for private advocacy services. Fees can range from $50 to $300 per hour, depending on the advocate's experience, education, niche, and location. Based on the advocate's track record, you should feel comfortable that you will be getting your money's worth just as you would with any other professional service provider.

Future Trends

It's clear that private patient and healthcare advocacy is here to stay. Patients have gravitated to our model in large part because of the allegiance factor — our

ADVOCATE DIRECTORIES

- **AdvoConnection https://advoconnection.com/**
- **Aging Life Care Association (ALCA) https://www.aginglifecare.org/**
- **Health AdvocateX https://www.healthadvocatex.org/directory-professional/**
- **Greater National Advocates (GNA) https://www.gnanow.org/**
- **National Association of Healthcare Advocacy (NAHAC) https://www.nahac.com/find-an-advocate**

Two regional chapters of NAHAC have also been formed:

- **Massachusetts Health Care Advocates https://www.mahealthcareadvocates.org/**
- **Bay Area Health Care Advocates https://bayareahealthcareadvocates.org/**

only allegiance is to the patient and family, not to a hospital system, insurance company, or other institution. Trisha Torrey, the founder of the Alliance of Professional Healthcare Advocates, coined the acronym FUDGE as another reason for the growth of private advocacy. Patients often feel **F**earful, **U**ncertain, **D**oubtful, **G**uilty, and **E**xhausted and turn to an advocate for help.

There has also been a larger awakening in the medical system to focus on patient-centered care. Over recent years there has been a move toward partnership in care, centered on a recognition of the knowledge and expertise that patients have and can contribute to the management of, and decision making about, their health (Hewitt-Taylor and Bond, 2013). This has pushed medical professionals and younger doctors to realize that the Internet and social media have empowered patients who are now better informed about their health and expect better treatment, answers, and communication.

With regard to Internet research, "apomediation" is a new socio-technological term that was created to characterize a "third way" for users to identify trustworthy and credible information and services online (Eisenbach 2008). Apo is a Latin term that means "separate, apart, or away from" and apomediation is crowd-sourcing guidance from peripheral mediators (Anderson, 2008). For example, an apomediary might be a layperson who writes a well-respected blog about a disease for which he or she has developed an expertise.

The emergence and professionalization of patient advocacy means that patients now have a lifeline when faced with a medical crisis or other obstacle in the healthcare delivery system. With a competent, compassionate advocate as a guide, they may expect better outcomes, reduce stress, and focus on healing. We will continue to build our profession, ensure that its members adhere to specific standards, ethics, and best practices, and educate consumers so that they know who we are and how we can help, and teach them to become their own advocates. •CSA

RESOURCES

Aging Life Care Association https://www.aginglifecare.org/

Alliance of Professional Health Advocates (APHA) https://www.aphadvocates.org/

Code of Conduct and Professional Standards - APHA - https://www.aphadvocates.org/health-advocate-code/

Code of Ethics - Health AdvocateX - https://www.healthadvocatex.org/code-of-ethics/

Code of Ethics - NAHAC - https://www.nahac.com/nahac-code-of-ethics

Ethical Standards for a Board Certified Patient Advocate https://www.pacboard.org/wp-content/uploads/20191115PACB-Ethics.pdf

Greater National Advocates https://www.gnanow.org/

Health AdvocateX https://www.healthadvocatex.org/

Master List of Health Advocate Programs, curated by APHA. https://www.healthadvocateprograms.com/

National Association of Healthcare Advocacy (NAHAC) https://www.nahac.com/

Patient Advocate Certification Board (PACB) https://www.pacboard.org/ Consumers can verify an advocate's certification on this website.

Patient Advocate Foundation (PAF) https://www.patientadvocate.org/

Patient Navigation Institute - Dr. Harold Freeman - https://hpfreemanpni.org/

Elisabeth Schuler is the founder of Patient Navigator LLC. She became a Certified Senior Advisor® (CSA) in 2007 and is a Board Certified Patient Advocate (BCPA). She is a past president of the National Association of Healthcare Advocacy (NAHAC). In her first career, Elisabeth was a Foreign Service Officer for twenty-five years. The gift of her daughter's survival from a pediatric brainstem tumor in 1998 led Elisabeth to her new calling as a patient advocate. She can be reached through her website at www.patientnavigator.com or eschuler@patientnavigator.com

REFERENCES

American Hospital Association. (1972, November 17). *Patient bill of rights*. Retrieved from http://ethics.iit.edu/codes/AHA%201972.pdf

Anderson, K. (2008, August 28). Apomediation: Word of the day [Blog post]. Retrieved from https://scholarlykitchen.sspnet.org/2008/08/28/apomediation-word-of-the-day/

Eysenbach, G. (2008) Social networking, collaboration, participation, apomediation, and openness, *Medicine 2.0*. Retrieved from https://www.jmir.org/2008/3/e22

Freeman, H. P. (2012). *The origin, evolution, and principles of patient navigation*. Retrieved from EPI-12-0982 1614..1617 (aacrjournals.org)

Hewitt-Taylor, J. & Bond, C. (2013). Doctor, nurse or apomediary? - What role should healthcare professionals play in assisting patients with long term conditions to access, and make sense of, information from the internet. *Proceedings of the International Conference on Health Informatics* - Volume 1: HEALTHINF, (BIOSTEC 2013) ISBN 978-989-8565-37-2, pages 139-143. DOI: 10.5220/0004184701390143

Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (Public Law 109-18). Retrieved from https://www.congress.gov/109/plaws/publ18/PLAW-109publ18.pdf