

Patient Advocacy—An Essential Service in Integrative Care

Jennifer Brokaw, MD

Patients face considerable challenges when navigating through the U.S. healthcare system, and significant communication gaps contribute to this problem. To help address these issues, Jennifer Brokaw, MD, a former emergency-medicine physician, shifted her career to focus on patient advocacy as an integrative component of care. Now building a public platform to provide advocacy support and resources for families and patients, Dr. Brokaw shares her thoughts on: helping ease the navigation process for patients; the importance of clarifying patients' fears and desires; and, ultimately, improving health outcomes.

Q: Why did you leave your busy emergency-medicine practice to focus on patient advocacy?

Jennifer Brokaw, MD: I practiced emergency medicine from the time I graduated from residency in 1996 until 2008, and, during that time, I loved my job. When I first started in practice, emergency-medicine doctors were the ultimate patient advocates. It was our job to help patients receive the care they needed regardless of whether they were well-insured or not insured.

Over time, however, I observed several things. First, I noticed that the average age of the person visiting the emergency department [ED] was trending older because of the nature of the demographics of our country. I treated dozens of senior citizens in the ED whom I felt were poorly served by being there, as the ED is no place for an older person, especially one with cognitive impairment. Second, I observed that primary care was overburdened, and primary-care doctors were less able to deal with the complexities of some of their patients' conditions in an office-visit format. As a result, there were a lot more referrals to the ED for patients with complex illnesses who were experiencing worsening of their conditions. Third, I noticed that people were showing up in the ED with very little insight into where they were in the course of their illnesses, and their families were unprepared to help them make decisions or to strategize about getting the right care.

As emergency-medicine physicians, we have to put on a very narrow blinder for what we are addressing right then and there in the emergency room. I always felt, how-

ever, that there was often missed opportunities to provide more in-depth education and anticipatory guidance for patients and families so that they could participate more actively in what was going on instead of ricocheting around from the clinic, to the ED, to the hospital, and then back to the clinic.

So, in 2008, I set out a shingle. The name of my first business was Medical Consult and Advocacy Services, and my goal was to create a place where people could talk about their concerns and spend more time with a physician, becoming oriented to the status of their care and educated about their options, and receive assistance with second opinions or tackling insurance issues, etc. After about 2 years of practicing that way and taking a “come-one-come-all” approach, I built a team of thoughtful and enlightened healthcare professionals, including nurses, another physician, and a clinical pharmacist. It was a very integrative practice. At that point, we changed our name to Good Medicine because we realized that what we were doing *was* good medicine. Our focus was on listening to patients and families, understanding the context of illness, looking at the different fragmented parts of each person's care, and trying to build some cohesion and simplicity into that care—communicating both with each client and with the treating team about what the goals of care should be.

We also provided a formalized program of advanced care planning, which we marketed as a product to the general public to try to reach people more upstream from crisis into the idea of advanced care planning. We talked with patients about their goals, values, and fears around health and aging and then communicated that with the wider context of the family. This was an extremely successful program for the people who participated; however, our program was not very accessible to the larger public because of the cost. The process took a lot of time and resources, and it was not a model that the masses could afford. In 2014, the Good Medicine practice closed, and we looked at what our options were in terms of providing the service that we still wanted to provide.

My focus now is in developing a scalable model of the Good Medicine offering. In order to do this, I needed to stop providing direct patient care because this is a big undertaking; however, I feel strongly that patient advocacy is a necessary

service offering in the healthcare space that has not been fully met at this time.

Q: Are there certain populations who visit the ED who need more attention, care, and patient advocacy, compared with other populations, and who shine a light on the gaps in the system?

Dr. Brokaw: Certainly geriatrics and senior-care populations need more attention than the system may initially have to offer. People who are near the end of life from cancer, heart failure, kidney disease, or cardiovascular disease, often end up in the ED in the last months of life—and that is not the best or appropriate place to spend their time if they have limited time left.

When I give talks, I often tell the story of family members who came into the ED with their elderly parent who was failing. I just happened to treat this patient a couple of times previously, and the family members made it clear that they did not want their parent to be in the intensive care unit [ICU] or die on a ventilator. One day a patient was brought in by ambulance, and the paramedics were keeping her alive. The unit clerk called for the ICU team to the trauma room, and I basically warded off the ICU team and the emergency-medicine residents who wanted to intubate her. Instead I brought the family into the discussion and unnecessary measures were averted. The family and the patient understood that death was imminent, and, under no circumstances, did the family members want their parent to be put on a ventilator in the ICU. They wanted their parent to have a gentle death. So, that is what we allowed. We sent the ICU team away. The patient was given a warm blanket and the family was in the room comforting the patient.

When I walked out of the patient's room, the ED nurses that I was working with had tears in their eyes, and so did I. We looked at each other and asked ourselves why we had never done that before as opposed to rushing such patients off to the ICU, offering interventions, intubation, spending thousands of dollars, and robbing the families of the opportunity to talk with the patients because the patients were ventilated and/or sedated. It was not the kind of ending that this family wanted.

Ideally, there might have been a plan to keep the patient out of the ED altogether. I do not know where that planning broke down in that patient's primary care. The patient would have been a great hospice patient. It was just luck that I knew this patient's wishes, and I felt empowered as the doctor to know that not doing everything was what the family truly wanted. However, we should not be relying on luck so much in these scenarios.

Q: What are the major obstacles that prohibit the gentler scenario you just described from happening more frequently?

Dr. Brokaw: Number one, patients and families have to understand what their options are and what are the likely end-

of-life scenarios. These people need insight in advance that they might have to make decisions very quickly; they need to know what the ramifications of those decisions are; and they need to have a plan for that eventuality. Number two, patients need to have the ability to interact with the system in an empowered way and have a family member who is willing to speak up and direct care. Number three, physicians must be receptive and understand the ideas of patient and family autonomy, and be willing to listen and sometimes deliver less care than they normally would if they did not know a patient's preferences.

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reasons—is to do everything.*

Our default setting in medicine—for financial, legal, and ethical reasons—is to do everything. In the patient's and public's mind, doing everything means doing everything possible to keep somebody alive for as long as possible. We know that doing everything often means including things that we know are not beneficial and that may be harmful.

Q: Navigating the U.S. healthcare system to obtain desired outcomes can be incredibly challenging for individuals with both common and life-threatening problems. What are some of the reasons for the challenges and confusion that patients experience every day in this system?

Dr. Brokaw: On the system side, healthcare is a big industry with a lot of money and a lot of different people feeding at the trough. At the end of the day, we, as patients and families, spend a lot of unnecessary time and effort in order to satisfy the healthcare machine's necessities such as the paperwork. A person may have a simple medical problem that turns into a maze of confusion with unnecessary tests ordered before appointments, and then difficulties in obtaining appointments with various parties. We have created a lot of pain for families just to feed the machine, which is full of unreasonable incentives, non-patient-oriented mechanisms, and a serious lack of follow-up. Everyone walks around with a magnifying lens looking at his or her piece of the process and then not taking ownership of the whole journey.

On the patients' side, patients and families are not empowered to look at the overall picture of their health and to sit down and think about (A) what their goals are, and (B) what trade-offs they would be willing to make to achieve certain outcomes. As people age and their health becomes more of an issue, they tend to have an ever-optimistic and hopeful attitude about everything. They want our healthcare system to fix them and bring them back to being "new." So the 70-year-old who has a bad knee wants a new knee. Or, a person with heart

disease wants treatment and a stent to make him or her as good as new. Few people recognize, however, that “cure” is not always possible. Sometimes it is, but, often, it is not. Patient expectations need to be managed in a very thoughtful way, and we have to recruit the patient to the team of getting well and doing the necessary things to attain healing.

We are heading into a do-it-yourself era, I believe, in healthcare. People are going to seek information, access care, and order therapies from their smart phones. The same thing is going to happen with families caring for loved ones. The planning and execution of healthcare will move more into the patients’ and families hands to manage.

There are many interesting platforms and businesses that are trying to provide a way in which families and individuals can share information with each other and not rely on the medical system as much. PatientsLikeMe™ is a company that helps people with rare or complex disease access data and helps other individuals who are dealing with similar issues obtain the latest and greatest care that their doctors might not even be aware of. We have to face the fact that medicine today is very complex and sophisticated.

Q: In order to optimize the best health outcomes for people, what are some of the most important things that a clinician needs to be thinking about in terms of communicating with patients?

Dr. Brokaw: If I could prescribe one thing for every healthcare clinician, no matter the specialty, it would be to become trained in basic palliative-care core competencies. Clinicians need to learn skills such as how to: have difficult conversations with patients; listen to patients; and apply motivational interviewing techniques. Clinicians need to know how to engage their patients and bring them onboard. This will help clinicians understand each patient’s and family’s goals and fears and use learned or personal knowledge to help the family receive the best possible outcomes. Palliative-care conversations, difficult conversations, and end-of-life conversations are skills that need to be learned, practiced, and practiced again. I do not think very many clinicians have that training, and they certainly do not have the practice.

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I would love to see palliative care more integrated into medical education, both at the medical-student level and at the postgraduate level. There is no time like the present, however,

for current practicing clinicians to take continuing medical education courses in this area. I cannot think of a specialty that would not benefit from such training. Palliative care is about how people want to live their lives and what their goals are.

A person may have a common non-life-threatening problem that isn’t easily solved and may cause that person to be very emotionally distraught. Patients might do what clinicians have suggested and still not get better right away. This leaves patients feeling that: (A) they are bad patients; (B) there is something more deeply wrong; and (C) they are not able to function up to par, such as not being able to walk or exercise as usual, which makes them very distressed. In these cases, it is important for clinicians to communicate effectively, at the outset, the things that need to happen. If a patient becomes convinced through initial communication that a clinician is on the patient’s side, is empathetic, and is a source of experience and knowledge in the necessary area, then the patient is more likely to share information during follow-ups.

If, as clinicians, we were better at communicating, engaging, and convincing patients that we are on their teams, more patients might pick up their phones or e-mail us and say, “by the way, I am better. You were right,” or, “I am still not better. It has been 6 months, and I am really worried now.”

Q: Will you tell us more about the patient advocacy platform that you are developing and about how you hope people will benefit from this new venue?

Dr. Brokaw: There is a need for comprehensive support for patients and families who are dealing with a serious illness or an ongoing chronic medical problem or end-of-life issues. I, along with a team, am building a platform that will allow people to interact with real-time help and navigators that will offer a comprehensive solution to care and care-giving challenges. Such help will include medical decision-making, financial planning or troubleshooting, legal knowledge, and emotional and psychological support for both patients and caregivers. The idea is that we are going to engage people through promoted content and informational videos. We are also building an engaging experience and tool for people to be able to create value or wish statements for their care. We will also provide backend support for the challenges of care giving and harness all of the resources that are out there to help families in the moment.

The aspiration is to have a virtual platform with tools and interactive content, but also to have available help from advocacy coaches or counselors who are familiar with the four buckets of what we are addressing—medical, financial, legal, and emotional/psychologic issues—and who can help a person get started in clarifying and moving forward in their situation and/or be referred for more expert assistance if needed.

We want this new patient advocacy platform to be very user-friendly. Part of the reason I have put clinical medicine on hold at this time in order to build this platform is that I believe there is a significant need for a “one-stop-shop” for patients and their families to receive advocacy help and care.

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Q: How does the current medical model need to change to benefit both patients' ease of navigation and desired outcomes?

Dr. Brokaw: I wish that every clinician was an integrative clinician—in no matter what specialty—who understood that, we simply cannot focus on only treating an organ system or a specific problem. Every disease or medical problem is attached to a whole organism. A human being is a complex organism with a very-difficult-to-fully-comprehend set of challenges and an ecosystem of family and relationships that need to be con-

sidered as well. Integrative medicine does a good job of addressing these aspects.

One of the next steps in medicine will be to look more broadly beyond the patient; to include the whole family and the ecosystem of that patient; and to acknowledge the impact of disease and illness on the people immediately around the person who is actually ill. My hope is that the medical model will move in a direction that recognizes fully all of these layers and addresses them. I am very optimistic. I have a really good team put together, and I am excited about the people I have been able to attract to this advocacy project.

Jennifer Brokaw, MD, is currently working on a patient advocacy project in San Francisco, CA.

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