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Advocating for Patients— Implications for Hospitals

by Nancy Vessell

Most people upon landing in a legal mess wouldn't think of trying to fix it themselves, no more than they would try to untangle a complicated tax matter. But when making their way through the complexities of health care, most go it alone—unless they are among the few but growing number of people with professional health advocates on their side.

“When you think of a legal issue, you go to a lawyer, and the lawyer becomes your point person to navigate the legal system. However, when you think about the idea of trying to navigate health care, nothing like this existed,” says Martin Rosen, recalling when he cofounded Health Advocate in 2001.

Today, the suburban Philadelphia-based company advocates for millions of people through its 4,300 employer clients. It helps health care consumers find specialists, compare quality and costs, understand their health risks, get the most out of their insurance coverage, and resolve billing disputes.

Although it wasn't the first of its kind, Health Advocate is reportedly the largest health advocacy company in the United States. The small number of firms in the business started within the past 12 years, and several of them report steady growth and anticipate further expansion, particularly if health insurance becomes a mandated employment benefit.

If that happens, says Miles Varn, MD, chief medical officer for PinnacleCare, a Baltimore-based health advocacy firm, “it is going to make the need for having an advocate for the system all that more critical.”

Internal versus external advocates

Although they often share the name and some principles, independent advocates differ from hospital-based advocates in basic ways. Yet both say their roles will increase in value as consumers bear more of the cost of health care.

The Society for Healthcare Consumer Advocacy, a group within the American Hospital Association, has 828 members, but SHCA President Ruth Sullivan believes there are many more advocates throughout U.S. hospitals. “We have members from large academic facilities and small rural hospitals. Some have one advocate, some have dozens,” says Sullivan, who is the director of patient/family advocacy with Shore Health System in Easton, MD.

Hospitals employ various models of consumer advocates—some are called patient advocates or patient representatives. There may be one advocate for the entire hospital whose primary responsibility is to address complaints and resolve problems. Some hospitals have patient advocates assigned to departments—the emergency department is a common one. Those advocates tend to serve a more proactive, educational role designed to ensure that patients have a positive experience.

Says Sullivan, “We all do basically the same [job] in trying to facilitate communication.” The most common issue she handles concerns a patient’s or family member’s frustration over lack of information. Her picture and phone number are posted in patient rooms to encourage patients and families to contact her. “If it isn’t resolved at the staff level, then they have my number,” she notes.

Unlike most hospital advocates, Sullivan, a registered nurse, receives physicians’ written orders to intervene with some patients. For example, if a physician has difficulty explaining complex medical issues to a patient or family, the doctor may write an order for Sullivan to review the case and talk to the patient and family to help them understand. To improve direct communication between patient and doctor, Sullivan may assist a patient and family in formulating three questions they most want answered.

Patient advocates increasingly deal with financial issues as larger shares of health care costs shift to consumers and personal financial problems mount. Sullivan says difficult economic times make a patient advocate’s role more valuable to patients for resolving billing questions and connecting patients with resources to assist with payment. “People are frustrated with the additional stresses of not having funds,” she notes. “People who have always paid their bills on time are faced with not being able to pay them.”

Beverly Pasko has been the patient representative at St. Clair Hospital in Pittsburgh for 19 years and has seen a growing concern with bills. “Managed care has really changed what people might complain about. In the past few years, because of all the changes in health care, people are paying more for premiums and are getting less because of higher deductible policies,” she says.

Since Pasko is a one-person department, her time is mostly spent reacting to concerns and grievances. “Our hospital staff is really proactive,” she says, “and if [staff members] know someone is having a problem and they can’t resolve it, they refer it to me.”

As an advocate, Pasko provides patients with an avenue for raising a concern that’s independent of the bedside caregiver. “Sometimes they don’t want to complain to caregivers. They want to talk to someone not involved in their care,” she says.

While hospital-based advocates have the advantage of being on-site at the point of care, some patients want advocates with an even greater, arm’s length independence. That’s where private health advocacy firms have the edge. Their fees are paid by clients—usually employers and sometimes individuals.

“Our independence gives us the ability to put ourselves in the patient’s shoes a little more than if an advocate is working for a hospital or a health plan. [Those advocates] are subject to a whole slew of organizational pressures,” says Larry Gelb, president and CEO of CareCounsel. Gelb began the company in San Rafael, CA, in 1997.

Internal and external patient advocates are not mutually exclusive. While they may perform some similar functions, their roles are different, leaving plenty of room for both in the health care arena.

The role of the independent advocate

Patient advocacy firms provide a broad, comprehensive service to consumers aimed generally at getting patients the best care at the best value, regardless of the institution. Although services vary somewhat among firms, most assist at all touch points of the health care system, from setting up appointments with specialists and arranging for tests to securing coverage insurers and negotiating payments with hospitals.

The consumer calls the advocacy firm when a need arises, and a personal advocate then handles the issue

from start to finish. Most advocates have health care backgrounds, while some have been in the human resources and insurance fields.

“We look for people who have the experience and background and individuals who are listeners, can multi-task, can educate, can really do more than just answer questions, but serve as a resource and advocate for the member who calls,” said Jane Cooper, president and CEO of Milwaukee-based Patient Care.

The service is typically an employment benefit paid by employers—a set fee per employee per month. Coverage then applies to the employee, spouse, children, and sometimes to parents and parents-in-law.

Firms say their value to employers is threefold: increasing productivity from employees who don’t have to spend work time making phone calls to navigate the health care system; easing the burden on human resource departments in interfacing with insurers; and reducing health care costs by getting employees to the right place.

Rosen, Health Advocate’s chief marketing officer and executive vice president, emphasizes the cost savings. He points to a new client who had been suffering from severe headaches for 58 straight days. She’d been to nine doctors and had two MRIs. When Health Advocate asked her whether she’d been to a headache clinic in the region, she said she’d never heard of it, and none of the doctors she’d seen had recommended it.

“We got her an appointment, and two visits later she was on the road to recovery,” Rosen says. “If you backtrack and do the math, you can see an enormous amount of money is wasted by not getting you to the right place at the right time. And it’s not because [something is] preventing you; it’s because it is complicated and there’s a lack of knowledge about facilities and resources.”

Some health advocacy companies also sell a different model directly to individuals. It’s more expensive, because people who enroll in such programs typically have complex situations that require more time.

But Cooper believes the individual market will grow. “I think the advocacy industry will find more individual consumers as customers.... There will be a lot of creative types of plans offered as health care changes to embrace the uninsured.”

High-end personal advocacy

One company that deals primarily with individuals has found a niche with affluent customers. PinnacleCare goes beyond advocacy to health management, proactively helping clients manage chronic diseases, detect health risks, and attain health goals, such as weight loss. Fees range from \$8,000 to \$40,000 a year, depending on the client’s health needs.

“Our clients have experts who advise them in areas of importance, like lawyers and accountants, but there’s not been anyone to provide that level of expertise on the health care side until we came along. Our business is a relationship business, first and foremost,” Varn says.

The firm starts by organizing a client’s health information from a variety of sources, and then it’s reviewed and summarized by a physician. A risk analysis is performed to determine what screenings and preventive measures are advised.

“If [clients need] to lose 20 pounds, we bring in nutritionists, trainers, etc., to measure their success and coach them through it to ensure they have the best chance of accomplishing their goals,” Varn says.

A medical advisory board composed of prominent physicians directs PinnacleCare patients to centers of excellence with cutting-edge treatments. A research team also prepares reports on various medical conditions to educate clients about their illnesses and treatment options so that in visits with physicians, “conversations start at a much higher level, and they make better use of their time,” Varn explains.

He adds: “We make appointments, interface with providers, and make it easy for the patient to see a physician and go home without having to deal with inefficiencies... We try to minimize [patients] time in the system, so they’re able to enjoy life.”

Cost and quality comparisons

An emerging function of health advocacy is providing clients with cost and quality comparisons of health providers.

“Employers are changing benefit plans, and there’s an increased focus on performance and reducing medical errors,” says Cooper, whose firm provides cost and quality analyses to clients. She explains: “If Jane Cooper wants to have a diagnostic procedure, she calls her advocate at Patient Care and gives information on the procedure the doctor recommended. The advocate will compare local hospitals on cost and quality information....We put it all together in a letter for the consumer and talk to [her] about what it really means.”

Publicly reported quality data is obtained from the Leapfrog Group, while cost information is obtained directly from providers, she says. The ease of getting cost data from hospitals varies with the market. Some hospitals are accustomed to providing that information, she notes, while others still balk.

Health Advocate has recently launched a cost calculator using benchmark data on the cost of medical care. Although the calculator doesn’t provide exact charges by institution, it can tell consumers what they might expect to pay for particular procedures based on regional data and their own benefit plan, Rosen explains.

Advice for hospitals

Hospitals that interface with private advocates may find greater demands for quality and cost transparency as advocates shop for the best deal for their customers. Cooper notes that her experience suggests that fewer than 10 percent of hospitals have transparent cost and quality information. Health care, she points out, “is the one thing we buy without knowing what it costs. Hospitals have never really had to disclose that [information] to the public, and some still refuse to do so. There will be more pressure to do that.”

Advocacy firms maintain that hospitals benefit from third-party representatives who are knowledgeable and want satisfied customers as much as hospitals do. “When we set up the company, we worked hard on positioning ourselves as the middle person,” Rosen says. “We try to build our reputation so that hospitals and insurance companies do not view us as a negative entity...Our experience overall is that providers like what we do. No.1, we’re knowledgeable, so we’re not wasting time. No.2, we’re trying to get to the bottom of things.”

Gelb says outside advocates can positively impact a hospital’s balance sheet. “It’s more of a benefit for hospitals than a detriment, because the natural advocacy intervention is to try to get the health insurance company to pay additional monies.”

He believes more hospitals should have internal advocacy programs to help patients with broader issues. Gelb says his CareCounsel has been approached by hospitals to provide the internal service for them, but

his employer model is not easily adapted to a hospital model.

Varn believes more hospitals will embrace the role of independent advocates. “A number of hospitals we work with are becoming more and more customer service-oriented. There are systems that have not had concierge or navigator services and are asking for our advice in setting those up. If a hospital system is not focused on that in the same way they’re focused on patient safety, then I think they’re going to be playing catch-up,” he says.