
REMAPPING DEBATE

Asking "Why" and "Why Not"

Patients routinely treated disrespectfully?

Original Reporting | By Margaret Moslander | Health care

Nov. 9, 2011 — Countless times every day, a patient is made to wait long past a scheduled appointment time to see a physician or other medical professional, or is given only 10 or 15 minutes when he

HOW DOES IT FEEL?

We recently took a look at the fact that, despite innovative efforts at a number of medical schools, the medical community as a whole still has far to go to enhance doctor's communication with and empathy for their patients. That reporting included candid comments made by experts leading efforts to reshape medical education acknowledging that there are profound structural barriers within the medical care system that inhibit the effectiveness of reforms made at the training level.

Oftentimes, advocates for more humane interactions between doctors and patients focus on the medical benefits of doing so: better communication has been found to result in the patient providing more complete and accurate information for the doctor to work with. Furthermore, patients whose subjective experiences are positive have been found to have better outcomes.

But we wanted to put those (very significant) benefits to the side, and explore an additional aspect of everyday medical interactions: how are "inconveniences" commonly seen as "just the way things are" actually psychologically and emotionally harmful to patients?

— *Editor*

is seen, or is seen less as a whole person than as a set of symptoms, or can't get straightforward answers to his questions, or is faced with the overwhelming task of negotiating a complex medical system on his own.

Are these reasonable costs to pay for the benefit of eliminating any "inefficiency" in the medical system related to patients getting "too much doctor time"? Are they mere inconveniences, or something worse?

Powerless, frustrated, and "disrespected"

Having to wait past one's appointment time is a persistent problem, albeit one that is not often discussed. Press Ganey, a company that conducts patient satisfaction survey research and describes itself as providing "health care improvement services" to the health care industry, reported in a 2009 white paper that "one important aspect of the patient encounter that tends to be overlooked is time spent waiting before a patient sees a physician."

The paper cites survey data the firm collected that showed the "average wait time patients spend waiting to see their provider is 24 minutes," and that, "at some practices, patients are made to wait significantly longer, in some cases hours."

According to Press Ganey’s white paper, “when a patient is waiting to see a physician,” the delay can cause not only “mere annoyance,” but also, “physical and emotional discomfort and anxiety.”

Carolyn Marsh, spokesperson for the Picker Institute, a non-profit that advocates for and promotes patient-centered care, agreed that the habit of physicians and other health care providers of keeping patients waiting for their appointments was “too common,” and that the patient in those circumstances is “made to feel unimportant, overlooked and — if she or he happens to ask how much longer the wait will be — presumptuous.”

From the point of view of patients, March continued, “if they are sick enough to go see a doctor, the doctor should have the decency to treat their illness seriously and with dispatch.”

Julia Hallisy is the founder of the Empowered Patient Coalition, a patient advocacy group, and has worked on patients’ rights issues for the last 10 years. She identified long wait times to have blood tests conducted as “another common experience” faced by patients. “I hear patients say over and over again that they were waiting in the lab for an hour and a half after their appointment time to get blood-work done,” she said.

Patients, Hallisy observed, “are already stressed...often they have to get back to work, and can’t afford to take 2 extra hours out of their day, especially in this economy. Patients feel disrespected and extremely frustrated.”

After a rushed interaction, said Dr. Nancy Cochran, a professor at Dartmouth Medical School, “There is no question that patients feel devalued...We hear that anecdotally all the time.”

According to Hallisy, the impact is not limited to a single interaction: “Because this happens over and over again,” she continued, “patients develop this low-level chronic anxiety about having to deal with the health care system. They wind up worrying that the long wait time just to see the doctor is just the tip of the iceberg, and that there’s real uncertainty about what will come next.”

Ready, set, go

Scheduling patients for short appointments — perhaps only 10 or 15 minutes long — is today’s medical status quo. But, for patients, it is a status quo with serious consequences.

Dr. Elizabeth Rider, director of academic programs at the Institute for Professionalism and Ethical Practice at the Boston Children’s Hospital, pointed to a frequent occurrence: appointment time is limited and the patient either is not aware of the constraint on time or simply is not monitoring the time remaining in the appointment. That circumstance combined with what she described as the tendency of many doctors to latch on to the first concern that a patient voices results in many patients coming away from their appointment feeling as though they have not been treated well.

“A patient can come in and say ‘My child has a sore throat and a runny nose.’ It’s the physician’s job to ask, ‘Is there anything else?’” Most physicians, she said, “are loath to do that, because it takes time.” But this willingness to hear all of a patient’s concerns is crucial, she noted, because “you have to know what’s on a patient’s plate and what they care about.” The patient, she said, “might wind up saying, ‘well, [my child] has been having headaches,’ which is a crucial piece of health information and allows the parent to convey something that has been a concern.”

When the doctor has not taken the time to “ask a patient for their full list of concerns,” the doctor ends up either missing something entirely or having the patient “say something as they’re walking out the door, when you don’t have time to respond,” something that actually was the most important thing on the patient’s mind.

According to Dr. Elizabeth Rider of the Boston Children’s Hospital “absolutely essential for the patient’s emotional health and well-being” for doctors to be “present in the moment, with the patient,” even when feeling rushed or overwhelmed by their patient load and other responsibilities.

The patient, she said, leaves “feeling dismissed and not cared for by the physician.” It is, according to Rider, “absolutely essential for the patient’s emotional health and well-being” for doctors to be “present in the moment, with the patient,” even when feeling rushed or overwhelmed by their patient load and other responsibilities.

Dr. Nancy Cochran, a professor at Dartmouth Medical School who teaches a course on shared decision-making between doctors and patients, agreed with Rider that doctors “often assume that the first thing that a patient reports is the most important thing.” The problem, Cochran, said, is that “data have shown that that’s not true; it’s often the second or third thing a patient mentions that is the most important. Initially, the patient is trying to figure out if they can trust you as a physician, so the most sensitive issue won’t even be raised unless the doctor responds positively, empathically and warmly to the first encounter.”

Patients also suffer, Cochran said, when doctors “communicate a sense of time urgency to the patient, asking closed-ended questions like ‘You don’t have chest pain, do you,’ shaking their head ‘no’ as they ask the question, making it clear it’s not permissible to say ‘yes.’ Those kinds of questions leave most patients with only one acceptable answer.” The effect on patients? “There is no question that patients feel devalued,” Cochran said. “We hear that anecdotally all the time.”

The need for trust and support

Dr. Auguste Fortin, a professor at the Yale School of Medicine, identified a circumstance in which a patient does have the opportunity to mention a symptom (he also used a headache, as an illustration) but not what concerns the patient about the symptom. If the patient “worries that that headache is due

to a serious condition, but does not have a chance to convey that to the doctor, the patient winds up leaving the office with the same worry.” Furthermore, he added, “The result is that the patient does not feel fully heard, understood and cared for. The patient feels disempowered, stymied, unsupported and alone.”

Dr. Calvin Chou, a professor at the UCSF School of Medicine, emphasized the barrier to trust that can develop when a patient doesn’t feel that his or her time, effort, and complaints are being taken seriously or does not feel that he or she is being treated with respect. He said that from a “personal standpoint,” when he is a patient, he trusts physicians more when they “look at me, hear my issues, and resolve to do something about it.” On the other hand, when he finds himself “talking to the physician’s back trying to explain how my symptoms are affecting me,” that physician does not earn that trust, and consequently, does not earn a return visit: “I have not been back to those latter physicians, and, unfortunately, they have been more numerous than I would hope for.”

Negotiating the system

The Empowered Patient Coalition’s Hallisy, speaking both from her personal experience as the mother of a seriously ill child and from her years as an advocate, emphasized the difficulty that many patients have when they are forced to navigate a complex “hospital hierarchy” on their own.

“I struggled just to understand how all of these people fit together and what their title and role actually meant,” Hallisy said. It was, she continued, very difficult to “find the appropriate person to turn to,” and consequently she “spent a lot of time asking the wrong person [her] questions.”

Furthermore, doctors and nurses weren’t always helpful when it came to explaining the hierarchy.

“Often there are a lot of resources in hospitals to help patients,” Hallisy said. “But patients need to know about them, and that needs to be done in a more explicit way than simply handing them a brochure when they’re signing in, at a time when they’re already nervous, when maybe they haven’t eaten all day, and aren’t prepared to process that information.”

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Please tell me what is going on

Sometimes, the problem is not finding the right person to speak to, but the unwillingness of the right person either to be answer questions fully or to give the patient a concrete and understandable treatment plan.

“When you’re dealing with a critically ill patient, like we were, you want to understand the illness, to know what to look for at the bedside, what to alert the doctors about,” said Hallisy. “Those answers are difficult to get.” (See box below.) “Sometimes it was just withheld, sometimes it was given to us in

Adding to a family’s burden: the battle to get information

Julia Hallisy, founder of the Empowered Patient Coalition, has first-hand experience dealing with navigating complex hospital systems. Her daughter, Kate, was diagnosed with cancer as a baby, and was in and out of the hospital until she died at age 10.

At one point, Kate developed a hospital-acquired infection. Hallisy relates that Kate “was on life support in the pediatric intensive care unit for seven weeks, often hanging on by a thread.”

“We were panicked, we were terrified. I told people at the time it felt like I was in quicksand, and someone was throwing me a rope, but I just kept sinking.” She continued, “Being a parent, you feel that it’s your responsibility to take care of your child. We really felt like we were crying out for help, that we were desperate for information.”

That information, however, often eluded them. “Sometimes the information was just withheld, sometimes it was given to us in a very confusing way...sometimes people were just too busy.”

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A particularly difficult part of the experience, Hallisy said, was trying to convey to doctors that they “just wanted to understand what was going on, how to help, what kinds of things to look out for.”

Hallisy described her emotions at the time as “beyond frustration,” more akin to “emotional trauma.”

Elizabeth French, a lecturer in Health Behavior and Health Education at University of North Carolina at Chapel Hill, argued that, often, the “culture of health care organizations” led patients to feel “as if it’s not their place to push.” While the problem, according to French, is particularly acute for “vulnerable, more marginalized patients [such as] those with less education, lower income, those for whom English is not a primary language,” it remains an issue that “affects all patients.” Patients feel as though “they don’t know what to ask, or they know they need to ask questions but they don’t know when or to whom,” French said.

The impact, French continued, is that patients “feel helpless, hopeless.” Even though patients who do have the temerity to ask questions, French said, sometimes find that they are “slapped down by health care providers,” causing them to “feel embarrassed or stigmatized [or] disempowered.” This feeling, French said, leads patients to think, “I’m not going to stand up again.”

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Carolyn Marsh of the Picker Institute said that patients and their families are often forced to push hard to extract information about the patient's own condition and prognosis from doctors who are unwilling to be forthcoming with that information on their own. Marsh illustrated the point by describing the recent experience of a gravely ill, elderly patient in New York. The patient, Marsh recounted, "was very well known in New York." Despite the patient's prominence, and despite having paid for "the best doctors," information about his condition "was withheld from [him] and his wife in too many instances, right up to his death."

According to Marsh, "both he and his wife were anxious to know as much about his illness as possible, and almost no one made an attempt to keep them in the loop."

Regardless of the motivation of the doctors, Marsh said, the result was that they failed to meet what she called the "duty is to respond to questions with complete answers that will allow patients and/or their families to understand fully the scope of the situation." The patient's widow was left "with needlessly bitter memories of the whole sad experience."

Taking responsibility: individual and systemic issues

No one Remapping Debate spoke with failed to emphasize systemic deficiencies in the way medical care is delivered as a primary driver of the problems discussed in this article. Nevertheless, some experts we spoke to insisted that doctors have a personal level of responsibility to see that patients are treated with respect.

"If it's an ongoing pattern [of lateness]," Chou said, "Then it is the doctor's responsibility. You can't just say, 'That's just how things are with me, I'm always running late.' That's a professionalism issue on behalf of the doctor."

PATIENT "ROUNDING" — A MISSING ELEMENT OF BASIC COURTESY AND RESPECT?

The white paper from Press Ganey referenced in this article recommends a process it calls "patient rounding."

"After a patient has waited 15 minutes (and every subsequent 15 minutes), a staff member should physically get up and walk into the waiting area. The staff should acknowledge that the patient is still waiting, provide an update about when the visit is expected to begin and ask the patient if there is anything that they need to be more comfortable. This directly addresses patient cognitive and socio-emotional needs."

This is a recommendation that does not address the underlying problem of long wait times, but is intended encourage medical practices and providers to show they are not indifferent to the value of the value of the patient's time or to the concerns that may arise in the patient's mind while he or she is waiting.

Remapping Debate would like to know more about the extent to which this courtesy is or is not provided and why. Please contact us with your thoughts and observations.

Elizabeth Rider echoed Chou's sentiment; "If we just behave like technicians," she said, "then we're not professionals." She added, "Paying close attention to the patient and understanding the patient's perspective is an important piece of medical professionalism and ethics."

Furthermore, Chou noted the difficulty in getting physicians to understand the importance of treating the whole patient, rather than just a list of symptoms, saying, "All this medical knowledge has been stuffed into our brains, so that we have this huge fund to be able to trade on when we go see patients. Everybody's focused on data for patient outcomes. Traditionally, we've been a lot less focused on what the patient's needs and values are."

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In the end, though, Rider and Chou agreed with other experts about the need for systemic change. Yale's Fortin, for example, said, "I know that we don't [make patients wait] on purpose, but in primary care remuneration per appointment is low and overhead is incredibly high, so that appointments need to be short to keep the income flow in the black."

Fortin identified systemic change as the only sure way to solve the problem of long wait times, saying, "Perhaps if our current healthcare non-system gets reformed, overhead costs will go down, primary care doctors will be adequately compensated for their expertise, and we can book fewer visits per hour, and be of more help to the patient, without chronically running late."

Chou also blamed the structure of the health care system for the kind of problems described in this article, saying, "I almost always hear that doctors do want to spend more time with their patients. This is exactly why many run late, especially if the scheduling is out of their control; in some institutions, doctors are expected to see primary care patients in 12 to 15 minutes."

When asked, however, whether it's reasonable for patients

to feel disrespected of that their time isn't valued when faced with exorbitant wait times, Chou said, "I fully agree. It's really not fair for patients to have to wait to try to get in." He added, however, "It is often the prevailing system that prevents doctors and patient from achieving what both generally want, which is more time with each other."

Fortin echoed the sentiment that doctors want more time with patients as much as patients want more time with doctors, adding, "Doctors feel that they are running at full speed all day. No one likes to be apologizing every day, but that's what we wind up doing."

This content originally appeared at remappingdebate.org/node/942