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HEALTHCARE COMMUNICATION REVIEW

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HEALTHCARE RELATIONSHIPS: RECAPPING FUNDAMENTALS

The 21st Century Patient: Coming of Age

EDITOR'S NOTE: *This article first appeared in the Summer/Fall 2005 issue of the Review, the topic of which was understanding and managing difficult healthcare relationships and encounters. We reprint it here because it is also the key to understanding how to build strong doctor-patient relationships that will not only help patients avoid difficult encounters, but help them get the most out of their healthcare.*

Times are changing. So are patients and the way we interact with our doctors. Where before we were expected to be passive and "patient," now we are urged to be active and assertive – to claim our rights to know and decide. This is a good thing because, as patients, we have much to contribute when it comes to the process of figuring out what is wrong and deciding what to do about it. Not only do we have important knowledge and insights, but we also have the greatest stake in the matter. It is we, after all, who will bear the consequences of healthcare decisions. Yes, it is very good that patients are becoming assertive. That being said, it is important to ask *how* we can assert ourselves without creating discord in the relationship – without creating otherwise preventable difficulties. A look at where we've been and where we're going may help answer this question.

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Doctors: What Drives Their Engines?

EDITOR'S NOTE: *This article first appeared in the Summer/Fall 2005 issue of the Review. We reprint it here because an understanding of the forces that shape physicians can help patients do their part to build productive healthcare relationships.*

As little as 20 to 30 years ago patients' complaints might typically have been that their doctors were detached, arrogant and wouldn't tell them what was going on. Today, patients are more likely to criticize doctors for not listening – either interrupting them, "*…I don't want him to hear half my sentence. I want him to hear the whole thing*," or dismissing them, *"If I'm worried about it because I feel [a] problem exists…I definitely want it to be taken seriously*." [1] The frequency of these complaints makes one wonder. Why would doctors not tell and not listen, for instance? A partial answer can be found by a look at some of the forces that have driven them over the years. We begin with Hippocrates.

From the time of Hippocrates, in the fifth century B.C. through the late 1800s, medical knowledge had little substance and doctors didn't know if cures were the result of effective treatment or something else. What doctors did know was that, under these circumstances, their power to heal patients would stem more from their ability to inspire confidence than from their medical abilities. They were therefore advised by their mentors to set themselves apart from their patients and to use their social and cultural status, along with their medical training, to establish their dominance. The tactics for doing so, varied.

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From the Editor

With much sadness, I begin by telling you that this will be the last issue of the *Review*, and that, at the end 2012, the Healthcare Communication Project will cease its operations. We are proud of what we have accomplished these last twelve years, and hope that you have found our various efforts to be of value to you. For those who would like to reread past issues of this publication, please note that we will maintain our website with postings of all our newsletters, as well as links to resources.

It's fitting we feel, to dedicate this last issue to the fundamental concepts that form the basis of healthcare relationships – relationships that are central to optimizing health outcomes. To that end, we recap articles from a variety of past issues. While these articles are specific to doctors and patients, they are applicable to many other clinical relationships – including those between family caregivers and clinicians.

We begin, then, with essays to remind readers of the changing expectations of doctors and patients as well as the factors that may hinder those changes. To follow up, we include articles that address the process of *how* to implement these changes, beginning with discussions of shared decisionmaking and then healthcare negotiations. In the end, our hope is that these pages will help all those traveling through the healthcare system successfully complete their journey.

As usual, we hope readers find this issue of value.
Be well. Judith Greenfield

Doctors, *Continued from Pg. 1*

Hippocrates, for instance, urged doctors to reveal "…nothing of the patient's future or present condition," and to engage in conversation with patients only so far as it encouraged patients' acceptance of prescribed cures.[2] Much later, in the 17th and 18th centuries, some doctors spoke out about the value in educating patients. Even so, these same doctors believed that patients wanted to be deceived and saw manipulation and deceit as the best way of getting patients to follow their instructions. Around the same time, one suggestion for creating an air of authority involved "[A]rriving in 'roadsters with their green saddle-cloths…[with] four footmen in similar livery, and spouting a little Latin'."[3] So it was that centuries of being arrogant and keeping patients in the dark was justified by a genuine concern for the patient's good.

All that began to change in the late 1960s and early 1970s when it was learned that participants in scientific studies were routinely deceived. This provided the impetus for ethical and legal questions of informed consent.[4] Around the same time, advances in science and medical technology enabled doctors to extend lives that would otherwise have ended – leaving some with such a low quality of life that it was the subject of much contention. Terri Schiavo is a more recent and very notable example.

As a result of the uproar generated by these and other types of events, today's physicians know they may not impose treatments on patients – that patients must give their *informed* consent before treatments can begin. And that requires them to tell their patients what is going on, what their choices are and to explain the risks and benefits of each. But change is hard for anyone – especially when asked to discard more than 2000 years' worth of teachings. Under those circumstances, it's not surprising that we often see changes in form but not substance. That is, some physicians may go through the motions of acting differently but, when looked at closely, we might see that little has changed.

Many reasons account for this, with historical influences topping the list. The fact that most medical schools now offer at least one course on communicating differently with patients has been an encouraging start. Yet, even when medical schools emphasize "patient-centered" care, as is the case with the University of Western Ontario's Department of Family Medicine, those teachings are often lost when students shift from learning in the classroom to learning in hospital settings. Why? The answer, according to one of its classroom professors, is that hospital-based faculty, often of the old school, instruct students in old-style behaviors.[5]

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21st Century, *continued from page 1*

For centuries, the prevailing view was that normally competent adults become vulnerable and childlike when afflicted with an illness, leaving them unable to understand anything about their medical condition or what to do about it. In that respect, the doctor-patient relationship mirrored the parent-child relationship. Because doctors were primarily men, it was called a paternalistic relationship. Around twenty to thirty years ago, that view began to change. Patients and their advocates were arguing that illness did not automatically render them incompetent to make decisions and that, given the potentially harmful effects of new, life-saving treatments, they should be given the opportunity to give their informed consent. This view now prevails and patients have begun making the not-so-easy transition from being submissive to being assertive.

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Some may approach this new role timidly, by prefacing their comments with something along the lines of, "*I know I'm not an expert, but….*" It's almost as if they are apologizing for speaking up. This approach can help pave the way by sending the message that the intent is to contribute to, rather than challenge, the discussion, but it also tells doctors that we are not so confident in what we are saying, making it easier for them to dismiss it. Others may decide to stand tall, to say what they have to say respectfully, without hostility, but also without apology. This approach sends the message that we have confidence in ourselves and expect to be heard – that we expect to be given the respect that we deserve. This approach seems just right! Yet those of us who follow this path may find that doctors sometimes take what we are saying the wrong way. How can this be?

> ***That view has changed… and patients have begun making the not-so-easy transition from being submissive to being assertive.***
>
> ***The question is: How?***

One explanation has to do with the attitudes, biases and past experiences that influence what we say and how we hear things. This is as true of doctors as it is of anyone – despite their goal of maintaining objectivity. The way doctors take what their patients say, therefore, may have nothing to do with the actual patients themselves. For instance, doctors may take requests for a particular medication as a challenge of their expertise – an interpretation that may have less to do with the patients actually making the requests than it does with the current climate. That is, in this age of patients' rights, doctors are often thought of as the bad guys. And they know it.

A variety of reasons, some inspired by doctors themselves, may account for this view. One reason, however, is the shift of the doctor-patient relationship to a business model in which patients are consumers and doctors are providers. Unfortunately, this model, although encouraged by patient advocates, is based on a "Buyer Beware" warning and encourages distrust. It also encourages some patients to think of looking for other doctors if the ones they have will not do, or give them, what they want.

One outcome of this unfriendly climate is that even respectfully offered opinions and requests may push buttons that others have created, leading doctors to misinterpret our intentions and, perhaps, to feel challenged and angry. A lesson to be learned from this, then, is that we may need to pave the way after all. The question is, *how*? To apologize still defeats our purpose and sends a wrong message. It is important that, as patients, we present ourselves as equals and experts in our own right. We should present ourselves, and be seen, as partners whose views and questions deserve consideration, not automatic dismissal. And therein lies a two-part answer to how we might pave the way for respectful, harmonious relationships and encounters.

First, we consider what we want to be – active, assertive consumers or active, assertive partners. If it is the latter, we pave the way by letting our doctors know that our interest is in exploring things with them, not in telling them what to do. Or our interest is in understanding, not in challenging. In other words, we explain instead of apologizing. True, this may not always have the desired effect but, even if that is the case, at least we will know that we have done our part. Another way of looking at this is to continue the parent-child comparison for the doctor-patient relationship. By becoming partners with our doctors, we will have made the transition from patient as child (paternalistic model) to patient as adult (collaborative model) – bypassing or discarding patient as defiant teenager (business model). We will have come of age.□

Doctors *continued from page 2*

Meanwhile, modern constraints related to science and time also conspire to thwart even well intentioned physicians from responding, as they might wish, to patients. Early scientific and technological advances allowed doctors to see and hear patients' symptoms for themselves. With tools such as stethoscopes and ophthalmoscopes, for instance, they no longer needed to rely on patients' reports of their symptoms.[6] As scientific discoveries progressed, so too did the importance of objective knowledge – knowledge grounded in proven facts and, ideally, free of bias. Previously missing, vital aspects of medicine were now in place!

With objective knowledge about diseases and the development of technologies to treat them, doctors are doing just that – focusing on treating *diseases* (as opposed to treating sick *persons*). With objective knowledge at hand, the tendency to distrust and dismiss unproven, possibly biased, subjective knowledge grew. Medicine was soon seen as having two distinct parts: the science of medicine (a systematic and objective basis for understanding the human body and its afflictions) and the art of medicine (being able to subjectively understand, and effectively communicate with, patients).[7]

Scientifically obtained, objective knowledge is valued so much that even patients tend to put great store in it. But the belief that objective knowledge is enough for good doctoring has provided yet another basis for not having to listen to patients.

Scientifically obtained, objective knowledge is valued so much that even patients tend to put great store in it. While they might prefer doctors who have personal skills, many patients would argue that those abilities are not needed for the task of diagnosing and treating ills.

Reliance on objective – or evidence-based – knowledge has had its effect on the way doctors respond to patients. Like the earlier advances that enabled doctors to see and hear symptoms without relying on patients to describe them, the belief that objective knowledge is enough for good doctoring has provided yet another basis for not having to listen to patients. This is one reason why, soon after patients start telling the story of why they came to see the doctor, they are often interrupted by a series of questions – questions that, from a scientific standpoint, doctors expect will provide the answers needed for determining next steps.[8]

Time plays a role here as well. Doctors are often concerned that letting patients say everything they want to say will not only be of little diagnostic value, but will also take more time than they have to give to each patient. The current insurance reimbursement system, where insurance companies negotiate fees for various healthcare services, has particularly affected primary care physicians. Insurers do not pay doctors for listening. As a consequence, primary care doctors must see more patients in a day in order to make ends meet. Seeing more patients in a day means less time to spend with each and, in turn, means less time to listen.

Between modern and historical forces that influence how doctors respond to patients, there seems to be little hope of significant change. But there is hope! Inviting patients to speak, listening to them and acknowledging their concerns, not only can have profound effects, but have been shown to minimally, if at all, increase time spent.[9] Fortunately, there are increasing numbers of physicians and other healthcare professionals who are showing that subjective information is also vital for the successful treatment of patients. Furthermore, they are showing that skills associated with the "art" of medicine – listening to and appreciating what patients are going through, for instance – can be taught.

So who will teach them? Medical schools, as mentioned earlier in this article, now include communication courses. For already practicing physicians, it's been a number of groups, such as the American Academy on Communication in Healthcare, www.aachonline.org, and, in a few instances, hospital-based physician educators. But we, as patients, can play a role here as well. By trying to resolve our own difficult situations…we can provide doctors with an opportunity to respond differently to us and, through that experience, to hone their skills for communicating with other patients.□

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[1] Judith A. Greenfield, *A Health Partnership: A Qualitative Study of Patients, Nurses and Medical Practitioners on Collaborative Decision-Making* (MI: UMI Dissertation Services, 1996), 45.

[2] As reported by Jay Katz, MD in *The Silent World of Doctor and Patient* (NY:The Free Press, 1984), 4.

[3] See note 2, pgs 11, 13-16.

[4] Albert R. Jonsen, "The Birth of Bioethics," Special Supplement, *Hastings Center Report* 23(6):S1-4 (1993).

[5] Judy Belle Brown, MSW, PhD, speaking at the AAPP Research and Teaching Forum, *Emerging Trends in Health Communication*, Maritime Institute of Technology, MD, October 11, 2003.

[6] Paul Starr, *The Social Transformation of American Medicine* (NY:Basic Books, 1982), 136.

[7] Eric J. Cassell. *The Nature of Suffering and the Goals of Medicine.* (NY: Oxford University Press, 1991), 21.

[8] H.B. Beckman and R. M. Frankel, "The Effect of Physician Behavior on the Collection of Data," *Annals of Internal Medicine* 101(1984): 692-696.

[9] See note 8.

Making Healthcare Decisions

EDITOR'S NOTE: *This article first appeared in July of 2001 – in v1n2. With patients now expected to be the decision makers – to give their informed consent – questions around how to make those decisions must be answered by individual patients. As in its first printing, this article seeks to help patients find those answers.*

In this age of patient empowerment, patients are increasingly being urged to take charge of their care. While still reliant on the medical knowledge and skills of physicians, gone is the pedestal upon which they were placed in the mid 1900s.[1] Patient empowerment has taken different forms, one of which is a consumerist approach (heightened by the advent of managed care) whereby patients feel little ties to their doctors and easily leave one for another if they are dissatisfied.[2] An alternate approach to taking charge, one which has been shown to have a positive effect on outcomes of care,[3] is where patients participate as partners with equal "say so" or, if agreement cannot be reached, the final "say so". This latter approach relies on a process of shared decisionmaking, described next.

Shared decisionmaking, central to the collaborative model of the doctor-patient relationship described in the first issue of this publication (January 2001), refers to the process of arriving at treatment decisions. This process involves the sharing and discussing of relevant information by both doctors and patients. Doctors might explain the different treatment options, available to their patients, along with the known risks and benefits of each. They might also indicate which option they favor and why.

Patient empowerment has taken different forms ...

One approach, where patients participate as partners with equal "say so" relies on shared decisionmaking.

Things patients might share include what they know of their bodies' response to certain medications; how their personalities either do or do not lend themselves to following particular treatments the way they are supposed to be followed; and whether they are willing or able to make lifestyle changes required by one treatment option but not another. Decisions reached through such a process are said to have been " ... informed by best evidence, not only about risks and benefits but also patient specific characteristics and values.[4]"

Consider, a case where the effectiveness of a recommended treatment will be less than it could be if the patient is unable to pay close attention to details and take the medication on time. The patient knows, however, that he or she always has problems remembering details and often misses doses of medication. The doctor and patient would then discuss this and, perhaps, decide that another treatment option would be easier for the patient to follow and would be more likely to be effective.

Shared decisionmaking is not without its critics. One writer, David Carvel, is representative of those who view doctors, lawyers, and other professionals as experts whose knowledge and skill far outweighs that of people who seek their services. To Carvel and others, it makes no sense to seek the advice of a professional and then not take it. Furthermore, he says, talk of doctor-patient partnerships and shared decisionmaking is "political correctness gone too far."[5]

Carvel gives us food for thought. How can it possibly make sense for patients to question their doctors' recommendations when that's precisely why patients go to doctors? While answers to this and other questions must be sought by each individual -- what is right for one person may not be right for another -- the *Review* provides, below, one set of answers regarding shared decisionmaking. Agree or disagree, readers are encouraged to use these as a starting point for figuring out where they stand on the matter.

How can it make sense to question doctors? They are the medical experts.

Patients may understandably want nothing more than to place themselves in the hands of doctors and be cured -- or if cure is not possible, to be brought to a state of health that enables them to maintain an acceptable quality of life. But doctors can't always do that. Knowledge aside, there is still a lot of uncertainty in the practice of medicine. And doctors will be the first to admit that they are neither God nor mind readers. Patients who follow recommendations that haven't taken into account their own non-medical characteristics, values and preferences, may find themselves in situations they might have chosen to avoid had they participated in discussions with their doctors.

Isn't it enough for me to tell doctors what my preferences are and just let them make their recommendations based on that?

It might be. But then, again, it might not. Sometimes what we think we want before we get more detailed information

See* Decisions *on page 6

Decisions *continued from page 5*

about risks and benefits is different from what we want after we get that information – especially if the risks and benefits of the recommended treatment are compared with those of alternative treatments, or the option of no treatment. The exchange of personal and medical information that goes on in the shared decisionmaking process often helps patients discover what their preferences are – what is really important to them. And that's a large part of what helps patients and their doctors decide on a plan of treatment.

Will questioning doctors' advice mean I don't value their professional judgment -- the judgment that causes me to seek them out in the first place?

Not if you believe that doctors' professional judgments should be informed by both their medical knowledge *and* relevant non-medical knowledge about you that can only be discovered through conversation. By questioning and discussing recommendations, you are simply providing doctors with more complete sets of data to consider before arriving at their final judgments.

Will shared decisionmaking, based on both medical knowledge and relevant non-medical knowledge about me ensure that things will turn out the way I want?

Unfortunately, there are no guarantees. There will always be a chance that a treatment's outcome turns out to be less than satisfactory. What shared decisionmaking does ensure is that you know, as best as you can, the possible outcomes (good and bad) of the treatment you've chosen.

Whose responsibility is it to initiate shared decisionmaking?

This question will undoubtedly spark much debate. It is the opinion of the *Review* that both doctors and patients share responsibility for initiating discussions but, *at this time,* doctors have a greater responsibility to do so. The historical authority of the physician makes it difficult for many patients to initiate discussions – especially ones that might appear to question doctors' judgments. For this reason, doctors have a greater responsibility to invite discussions. At the same time, it seems to us that the claim, made by patients, of a right to make informed decisions also imparts a responsibility for them to seek information.

What if I just don't want to be involved in figuring out what I should do?

That is certainly your decision to make. The views presented above may not reflect your feelings on the subject. That is why each and every person should find their own answers to these and other questions about decision-making in healthcare. If you haven't already figured out what you want from your doctors, thinking about these questions may help you do so now. If you then share your expectations with your doctors, you will have taken an important first step towards building solid doctor-patient relationships.

[1] Mark Holoweiko. "Good News -- the Pedestal is Gone." *Medical Economics* 75 (20): 54- (1998).

[2] See Note 1

[3] Moira Stewart et aI., "Evidence on Patient-Doctor Communication" *Cancer Prevention Control* 3(1):25-30 (1999).

[4] Angela Towle et al., "Framework for Teaching and Learning Informed Shared Decision Making," *British Medical Joumal319* (7212): 766- (9/18/99)

[5] D. Carvel. "Patient-Partners May be Political Correctness Gone Too Far," *British MedicalJoumal319* (7212): 783 (9/18/99).

Doctor-Patient Negotiation: A Problem-Solving Exercise

EDITOR'S NOTE: *This is excerpted from an article that first appeared in the July 2001, v1n2 issue of the Review.*

The first thing readers should know about negotiations with doctors is that they are different than negotiations you might engage in when buying a car or seeking a raise. In those cases, someone wins and someone loses. If you get a better deal on a car, for example, the salesman makes less from the sale. When you negotiate with your doctor, however, you both start out with the same general objective – the resolution of your health condition. In these cases, neither doctors nor patients are trying to best the other. Both seek a plan of action that will best suit the individual patient. Sometimes, though, there are disagreements as to what is best. When this happens, negotiations provide a way to reach an agreement and are more like problem-solving exercises than anything else.

NEGOTIATION TIPS

1. ASK yourself what you want and how important it is to you. **2. ASK the doctor** to explain your different options and why he or she might favor one over the others. **3. LISTEN** carefully.	**4. REPEAT,** in your own words, what you think the doctor is saying. Clarify any misunderstandings. **5. EXPLAIN and DISCUSS** where you are coming from – don't expect that the doctor fully knows and understands.	**6. ASK YOURSELF** again, what you want and how important it is to you. **7. REACH AGREEMENT** **8. SET A TRIAL PERIOD** after which, if there is no relief, another option will be tried.

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Communication: What's the Big Deal?

EDITOR'S NOTE: *Because communication IS a big deal, we reprint this article, which first appeared in the July 2001 issue of the Review.*

One might ask: why make a big deal about communicating? Like breathing, isn't that something we all do automatically? We think. We speak. We listen. We respond. Simple? Not so simple! In fact, communication is the subject of much study for it often reflects much more than ideas. It reflects, among other things, social structure. The ways we talk with our doctors, for instance, reflects the social structure of the doctor-patient relationship. Or, as some would say, it reflects the distribution of power in the relationship.[1] As described in our last issue, [v1n1], doctor-patient relationships in America are in transition – with a shift of power (in theory at least) from the physician to the patient and a growing push for yet another shift to a more equal sharing of power.

Doctor-patient communication is especially complicated these days by the changes that have occurred in our healthcare system. While we still talk about decisionmaking as if it is totally within the realm of doctors and patients, many patients have become painfully aware that managed care plans may have the last say. Nevertheless, it remains important for doctors and patients to communicate in ways that enable them to arrive at mutually agreeable healthcare decisions. For many people, though, this type of communication is not something that will occur automatically. It will not be like breathing. First and foremost, doctors and patients will need to stop acting automatically and give some thought to what they want from each other. After all, it's hard to achieve something if we don't know what we want to achieve. Having figured this out, however, the next step is to share it with one another. This may take several forms. One form may be an up front discussion of expectations, another may be a bit-by-bit process in which expectations are shared as the need to do so arises during a medical encounter. In either case, this is likely to be breaking new ground and, for a while at least, to be a work in progress – with expectations, relationships, and communication patterns developing as one goes along.□

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[1] Howard Brody. The Healer's Power (New Haven: Yale University Press, 1992).