

Educating and Enlisting Patients

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Introduction

Most patients want more information and guidance from their clinicians than they currently receive [1,2] and are more satisfied with their care when they receive it [3,4]. Having information can decrease the sense of helplessness and isolation that often accompanies illness and can increase a patient's ability to remember and adhere to treatment plans [5].

Nonadherence to medical regimens is a major clinical and economic problem in the United States. Prescription underuse is 40% or more for patients with diabetes, hypertension, arthritis, or patients on estrogen replacement and 20% to 30% for patients with asthma or in need of anticoagulation [6]. Common reasons for this underuse include concerns about side effects, efficacy, and cost [7]. The major factors influencing adherence once prescriptions are filled are the patient's perception of the seriousness of the condition and of the efficacy of treatment, the chronicity of the condition and of treatment, and the quality of the clinician-patient relationship [8].

Education alone rarely is sufficient to ensure patient adherence. Clinicians also must enlist patients to be active participants in their care. Education and enlistment are conceptually distinct but interdependent activities, and the communication skills necessary to accomplish them overlap considerably. This article will review some approaches to education and enlistment, using clinical examples to demonstrate the utility of the techniques.

Discussing the Illness

Clinicians tend to overestimate the amount of time they spend giving information to patients. In one study, physicians estimated that they spent an average of 7 minutes educating patients, but the actual time they spent educating was 1 minute or less [1,9]. Although taking time to educate patients is important, time is not the critical issue. We think of patient education as a set of techniques or procedures that can be learned and used in a systematic way during each patient visit. In the long run, these techniques may save time by reducing nonadherence, reducing dissatisfaction, and reducing repeated visits without progress.

Ask, Don't Tell

Nearly all patients, no matter how sophisticated, come to the visit with ideas about the cause and prognosis of their illness.

This "explanatory model" helps the patient make sense of the experience of being ill and assign meaning to it [10]. Meaning can be functional (what I can't or must do because of the illness), symbolic (this shows that I'm a bad person), or relational (this is like what happened to my father when they found his cancer). The patient's explanatory model usually is based on his or her knowledge, experience, and beliefs as well as on discussions with family members or friends, one or more of whom are likely to be informal health advisors who have encouraged the patient to try one thing or another or to seek professional care.

Successful information giving begins with the clinician eliciting the patient's explanatory model. This does not necessarily mean agreeing with it, but acknowledging, understanding, and respecting it. Exploring the patient's explanatory model begins when the clinician elicits the history of the present problem:

Doctor: *So, Mr. Jones, you've been tired and achy for almost a month now. What do you think is going on?*

Patient: *I don't know, Doctor. That's why I came in.*

Without being discouraged, the clinician persists:

Doctor: *Of course, but it helps me to know what you think about this or what you've already tried. What sort of hunches or ideas do you have?*

Patient: *Well, to tell you the truth, I've been wondering about Lyme disease. This article in the newspaper says it can cause a lot of these problems. And it says your doctor might not know what it is or how to diagnose it. I brought it in for you to read. The treatment is antibiotics.*

Doctor: *So you want to make sure this isn't Lyme disease. Any other thoughts or concerns?*

Patient: *Well, my wife said I might be low in some hormone or vitamin. She's been giving me these pills from the store, but they don't seem to do anything.*

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Table 1. Eight Questions All Patients Have

Questions about the illness

1. What has happened to me? (diagnosis)
2. Why has it happened to me? (etiology)
3. What is going to happen to me? (prognosis)

Questions about medical care

4. What are you doing to me?
5. Why are you doing that (and not something else)?
6. Will it hurt or harm me? How much? For how long?
7. When will you know the results?
8. When will I know the results?

The clinician shows respect for the patient's explanatory model by using the patient's words and ideas in explaining the symptoms. The dialogue provides an opportunity for both speakers to supply or correct any missing or erroneous information and to understand mutual expectations for care.

Doctor: *Your thoughts about your health are important. I'll put this clipping in your chart. We stay updated about Lyme disease here in the office. Although you do have some features of Lyme disease, other features make it not likely. Some blood tests can give us more information about Lyme and other diseases that can cause these symptoms. What I do find, though, is that you also aren't sleeping or eating well and you've stopped doing the things you usually enjoy doing. I'm suspicious that the depression you had last year is coming back. I know you've been thinking about Lyme disease. What are your thoughts about the possibility that it is a return of depression?*

In the example above, the physician acknowledges the patient's ideas and then provides new information, offers a different explanatory model, and asks the patient for his reaction. This sequence (elicit the patient's explanatory model, describe your own impressions, and ask the patient how your model "fits" with his) has been described by Becker as an education and enlistment strategy [10].

Anticipate the Patient's Thoughts and Feelings

Receiving personal medical information evokes feelings as well as questions. Emotions such as surprise, fear, distress, and shame may flood a patient's awareness after hearing a diagnosis, even a suspected one. Remember that feelings are usually expressed nonverbally in facial expressions, body movement, posture, and breathing:

Doctor: *Mr. Smith, I can see this comes as a surprise for you. Later on you or your wife might have some questions about all this. When that happens, write them down so we can talk about them.*

Ask about feelings even if the patient is focused on gathering information:

Doctor: *Mr. Doe, I can see you have lots of questions about this, and I want to answer them. At the same time, I wonder what it's like for you to get this kind of news. If you or your wife want to talk about how this is affecting you, I'm ready to listen.*

Clinicians often believe that negative or painful feelings, like symptoms, need to be fixed or removed or that exploring feelings will take too much time or effort. Responding to patients with empathy does not prolong the medical visit but does reduce patient anxiety and distress [11]. Patients need to feel heard and respected in order to adhere to a treatment program. When a patient displays his or her feelings, even subtly, a clinician should acknowledge and name the feelings, check with the patient to make sure he or she is understanding the feelings correctly, legitimize or "normalize" the feelings given the circumstances, comment on steps already taken to cope, and express willingness to help [12]:

Doctor: *Mrs. Jones, I can see this comes as a surprise to you. You come in feeling perfectly fine, and now I'm telling you that you have diabetes. When it comes on without symptoms like this, it often is a shock to find out. Is that how it is for you? . . . Lots of people are surprised to find out they have diabetes. You did the right thing to come in for a checkup. I'd like to work with you on this so it doesn't cause you any symptoms in the future. Here's what we need to do . . .*

Answer the Patient's Implicit Questions

Information giving can be inefficient when the information fails to answer a patient's question or need to know. One way to become more efficient in giving information is to organize the process around the eight questions almost all patients have, no matter how medically sophisticated they are (Table 1).

There are three questions about the illness:

1. "What has happened to me?" (diagnosis)

To personalize the answer to this question, summarize the clinical data, give the problem a name, and tell its significance (Is it common? Dangerous?). Naming the problem decreases the isolation and loss of control that a patient may feel. On the other hand, diagnoses can be misleading; for example, "a little arthritis" may conjure up visions of a progressively crippling disease.

Doctor: *Mr. Brown, the exam of your back is normal, and you haven't had any symptoms that would indicate that cancer, osteoporosis, or even a slipped disk is causing your back pain. Back pain can come from lots of different joints and muscles, and it*

isn't necessary to pinpoint exactly which one is hurting. The treatment is all the same.

2. "Why has it happened to me?" (etiology)

The sense of vulnerability that accompanies illness nearly always gives patients twinges of guilt, shame, or grief. These feelings lead patients to ask themselves if they could have avoided getting sick (I shouldn't have gone out without my coat; I should have followed my diet). Sometimes these feelings take the form of the questions "why now?" or "why me?" (and not my neighbor or colleague). These concerns can lead patients to blame other people, events, or circumstances for their symptoms. Likewise, shame causes some patients to hide or deny the illness, and grief drains a patient's motivational strength. Validating the patient's feelings helps the patient move on to the issues at hand.

Doctor: *This sort of thing happens to lots of people. Back pain often comes from using a muscle or joint that your back isn't used to using. The activity may be minor. I don't think you did anything wrong to cause this, and you did the right thing by coming in and getting it checked. We should review how you lift things at home to make sure you don't hurt yourself, and I'll show you some exercises to keep your back limber.*

3. "What is going to happen to me?" (prognosis)

These concerns are both short term (My back hurts too much to do my job) and long term (Can I keep my job? Support my family?). Often, these concerns center around taking care of other people. In the example below, the physician helps the patient understand that this illness will not have a major effect on his life:

Doctor: *More than 90% of people with back pain like yours are back to normal within 3 to 5 days and don't get chronic back pain or arthritis.*

There are five questions about medical care:

4. "What are you doing to me?"

This isn't "shop talk" with a colleague; instead, it is a respectful orientation to the process of care.

Doctor: *The exam of your back and legs is the most important step at this point. That tells whether or not anything is pressing on the nerves coming out of your spine.*

5. "Why are you doing that to me (and not something else I have heard/read about)?"

The patient's explanatory model for the illness may include preconceived notions for how to proceed with diagnosis or treatment. Friends with similar symptoms may have had

different tests or treatments than those the clinician recommends. The patient needs to be reassured that the clinician is not being too aggressive or overlooking something.

Doctor: *You told me your buddy had an MRI of his back, and they operated on it right away. Our consultants have advised us that as long as your medical history and physical exam are normal and you follow the usual course, an MRI doesn't really add any new information. We would proceed the same way even if we saw a slipped disk on your MRI. If your symptoms change or don't go away, though, we may want to do a test like that.*

6. "Will it hurt or harm me? How much? For how long?"

The harm that patients experience can be physical, but harm also can be economic (How much does it cost? Will I need to miss work?) and social (Do you have to write down that I am being tested for HIV?).

Doctor: *You can expect to have some pain and stiffness in your back for 3 to 5 days. We have found that bed rest actually doesn't help patients recover faster; in fact, it can slow down your recovery. You won't harm anything in your back by doing your usual activity. However, you shouldn't be lifting heavy objects like you sometimes do at work. I can write a note for your employer about that if you need it.*

7. "When will you know the results (of tests, referrals, or treatments)?"

8. "When will I know the results?"

These questions are linked. The first is a question about things out of both the clinician's and patient's control. The second question is really about the patient-clinician relationship, or what the patient can count on the clinician to do.

Doctor: *You can schedule the MRI at the front desk. The results will be sent to me a few days after the MRI is done. My usual telephone hours are Tuesdays and Thursdays from 4 PM to 6 PM. Can I call you then with the results?*

Assess the Patient's Understanding

It is not enough simply to give information; it is also important to check that the patient understood intended meaning. Most patients have someone they "report to" when they get home. Consider asking patients whom they report to and what they plan to say about "what the doctor said."

Patients who are bewildered or overloaded with information may respond with "Yes" or "I think so" to the question, "Do you understand what I've said?" Instead of asking if the patient understands, the clinician can acknowledge that some of the explanation may be difficult to convey or difficult for the patient to comprehend [10].

Doctor: *Sometimes I forget to mention things. Tell me what your*

Table 2. Techniques to Facilitate Treatment Adherence

Simplify the regimen
Address one problem at a time
Tailor the regimen to individual habits and routines
Anticipate problems and devise solutions
Write down important information
Describe what the patient can expect from treatment
Review common side effects
Involve significant others in planning

understanding is at this point, just so I'm sure we're on the same wavelength and I haven't forgotten to tell you anything.

Discussing Treatment

In a recent review, Quill and Brody address a common dilemma for clinicians: finding a middle ground between paternalism (the clinician makes all the decisions for the patient) and autonomy (the patient makes all the decisions regardless of the clinician's advice) [13]. Quill and Brody acknowledge that patients need to know two important things in order to participate effectively in their care: 1) the treatment options available to them, and 2) what treatments the clinician recommends and why. A patient's desire for information, however, should not automatically be interpreted as a desire to make decisions [14,15]. Therefore, it is useful to separate the act of providing information from the act of providing advice. This is important to keep in mind because clinicians often describe treatment options in ways that convey advice implicitly. For example, patients change their choice of treatment options depending on whether the outcome is expressed as "chances of death" or "chances of recovery" [16].

Negotiating a Plan

When there is a difference of opinion between the patient and clinician on next steps, a treatment plan must be negotiated. Although the goals of treatment usually are shared (ie, to make the patient feel better or to prevent disease), areas needing negotiation can include the nature or name of the disease (the doctor thinks the problem is narcotic addiction; the patient thinks the problem is inadequately treated pain); the methods of treatment (the doctor wants to prescribe a cope and rehabilitation regimen; the patient wants disability and more narcotics); and roles (the doctor wants the patient to change his or her behavior; the patient wants the doctor to "fix the problem now"). Methods of negotiation can include a trial of treatment, getting another opinion, verifying mutually shared goals and brainstorming about ways to reach them, and making concessions [17].

Important parts of the discussion of treatment plans include deciding what each party is willing to do, clarifying who or what might help to accomplish the plan, anticipating and solving problems that might arise, and rehearsing the plan [18].

Facilitating Adherence

The following techniques are useful in facilitating treatment adherence and are summarized in **Table 2**.

- **Simplify the regimen.** Adherence with once or twice daily medication regimens is nearly double adherence with regimens of 3 to 4 times per day [8,10].
- **Address one problem at a time.** Trying to change too many things at once can leave both patient and clinician feeling stuck or helpless. Address one objective at a time (eg, weight loss or cholesterol reduction or blood sugar control) and break the required tasks down into realistic steps. Self-monitoring of progress (eg, tracking exercise frequency or cholesterol levels) can help patients improve adherence and experience self-efficacy as efforts are translated into results.
- **Tailor regimens to individual habits and routines.** "Walk through" a typical day to identify routines that can be linked to the treatment plan and to identify and overcome obstacles to successful implementation of the plan. Include a plan for what to do about missed steps (eg, a missed dose, a missed day of exercise).
- **Write down information that is important for the patient to remember.** Or better yet, help the patient write it down. Recollection of information and instructions enhances treatment adherence [5,8,19], but patients typically forget one third or more of what they hear in the office by the time they arrive home [2,19]. To help patients remember the information, give information in short, digestible chunks. Avoid medical jargon and try to convey meaning in ordinary words. Use letterhead or prescription pads to emphasize a personal and professional investment in the patient's health. Write the patient's name on handouts and encourage the patient to display them in a prominent place, such as on the refrigerator. Personalize preprinted handouts by highlighting relevant information.
- **Describe what the patient can expect as a result of treatment.** For example, a conversation about antibiotic treatment for a urinary tract infection might proceed like this:

Doctor: *Mrs. Green, you have an infection in your bladder that causes pain when you urinate. We can treat it with antibiotics.*

For the first few days, you will feel like they aren't really helping and you'll be tempted to stop using them. Don't stop then. After 4 to 5 days you will feel well again and think the infection is gone. Don't stop then, either. It's important to take the pills till they're all gone, or the infection could come back.

- **Review common side effects of treatment.** Patients who are told about possible side effects are more likely to experience them but are less likely to stop treatment when they occur. Tell patients about the two or three most common side effects and what to do about them:

Doctor: *Mrs. Green, this medicine can upset your stomach. You should take it with food. If it causes diarrhea or a rash, which probably won't happen, I'd like you to call.*

- **Involve significant others in planning.** People close to the patient may remember more of what is said and can help with anticipatory problem solving. Ask patients if they would like to have a significant other with them when treatment issues are discussed and be sure to elicit that person's perspective.

Discussing Nonadherence

Patients should be asked about nonadherence in ways that do not suggest shaming or punishment. One approach is to acknowledge the frequency of nonadherence: "Most patients have trouble following a treatment plan. What problems have you had?" Some patients hide nonadherence for fear of "making the doctor angry." Be clear that your role is to help solve problems and encourage healthy behaviors, not to punish unhealthy behaviors. Acknowledging nonadherence and helping to identify and overcome barriers to adherence assures patients of your continued support.

Recent advances in behavior change theory suggest that three questions are useful in helping patients who are having trouble changing health behaviors. The first is simply to ask a patient whether or not he or she wants to do anything to change the behavior. The second is to ask how important it is to the patient to change. The third question to ask is how confident the patient is that he or she can make the change. Based on the answers received, clinicians can apply behavioral change techniques specific to patients' individual needs [20].

Conclusion

Clinician-patient communication affects important health outcomes, including information exchange and recall, reduction of distress, improved satisfaction and treatment adherence, and ultimately, improved biologic outcomes. Programs to enhance clinicians' education and enlistment skills are now widely available, and the number and types of educational programs for patients are expanding. The persistently

low rates of nonadherence to treatment indicate that there still is plenty of work to be done.

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