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## Not Just Small Talk: Quality-of-Life Questions at Medical Exams

By JANE E. BRODY



*"How are you doing?"*

*"O.K."*

That kind of exchange, which takes place at all too many medical checkups, may sound harmless. But for patients with chronic health problems — arthritis, heart disease, cancer, irritable bowel syndrome, diabetes, attention deficit disorder — it suggests that the doctor is not doing his or her job. When physicians fail to ask probing questions about quality of life, addressing only the physical aspects of a chronic illness, they are likely to miss serious problems that can be remedied — among them depression, sleep disruption, loss of sexual desire and difficulty with everyday or pleasurable activities.

"More and more patients report that they do not feel heard," Jackson Rainer, professor of psychology at Georgia Southern University, said in an interview.

"Patients need to be assertive if their symptoms are not what are typically

expected. Many, especially the elderly, have mental health issues that occur in concert with their physical problems, yet these are rarely addressed by their physicians.”

Of course, everyone knows that a doctor’s time these days is limited. But for medical care to be delivered efficiently and economically, assessing health-related quality of life is an essential element that can help doctors identify therapy that is counterproductive or ineffective or needs to be modified.

In a paper in *The Mayo Clinic Proceedings*, a team of experts led by Elizabeth A. Hahn, a medical sociologist at Northwestern University, called for a systematic quality-of-life assessment to detect physical and psychosocial problems that might otherwise be overlooked. The authors noted that the assessment could also be used to monitor the effects of disease and its treatment, determine when therapy needs to be changed and improve doctor-patient communication.

A quality-of-life assessment can be used to decide when to go to the next therapeutic step, or to alter treatment to minimize distressing side effects. For many chronic problems, the process can begin with a brief questionnaire that patients can complete while waiting to see the doctor, who can then quickly review the responses and focus on what is most important or troublesome.

The information gleaned can be used to redirect therapy to make it easier for patients to live with a disorder, or to encourage them to adhere better to prescribed treatments, or, as might occur with advanced cancer, to decide to forgo further disease-directed treatment.

For example, after a review of quality-of-life issues, a patient with early-stage prostate cancer may choose “watchful waiting” instead of surgery, to minimize the risk of sexual dysfunction and urinary incontinence. Or someone newly found to have Stage 4 lung cancer that is already widespread may choose only comfort care, rather than suffer the toxic effects of therapy during the remaining months of life.

## **Taking Stock**

To take a more common example, among the nearly 50 million Americans with arthritis, “progression of the disease can sometimes be slow,” and “many patients are not aware of the impact their arthritis has had upon important dimensions of their lives,” Kevin Fontaine, a psychologist at Johns Hopkins School of Medicine, wrote on the university’s Arthritis Center Web site. “One patient may have given up playing tennis because of knee pain and not noticed, until the results of his health-related quality-of-life assessment were discussed, that he had also abandoned many activities — attending sporting events, mowing his lawn — that he had previously enjoyed.”

When I faced precisely that problem about five years ago, I made my own inventory of how arthritis had affected my life. I could no longer play tennis, ice-skate or walk three miles with my friends each morning. Any activity that involved a lot of standing, like cooking for company or going to a museum, was out. And it was agony to stand up again after sitting for a long while, as at a movie, concert or theater. So I opted for a double knee replacement, and despite the excruciating pain that accompanied the surgery, I’m now very glad I did.

Even if it is not possible for patients to resume all their activities, they can be helped to discover “a new normal,” Dr. Rainer said. As he wrote in *Arthritis Self-Management*: “Arthritis can become a bridge, rather than a barrier, a bridge to new and different strivings for a satisfying life. Satisfied people have a high tolerance for frustration and a clear perception of reality that allows them to both acknowledge and respect their limits.”

Among the questions that can be used to help patients adjust better to a chronic health problem and its treatment, he wrote, are these: “Given the nature of your illness, what makes you feel good now?” “What does ‘feeling good’ mean to you?” “What are your strong points? Your talents?”

Factors to consider include your capacity for productive activity, how well you manage symptoms, your response to pain and tolerance of depression and anxiety, and your social connections — “the people, places and events that are most important to you,” Dr. Rainer wrote.

Moreover, Dr. Fontaine wrote, identifying a disease’s effects on patients’ quality of life can result in treatments and self-management techniques that may enable

them to reclaim their former lives. Arthritis patients, for example, might try to be more physically active and better control their weight. Or, as Dr. Rainer put it, "Quality of life depends on how well you can integrate new circumstances into your life."

### **Adjusting to a New Normal**

People's responses to life's challenges are largely a function of their innate characteristics, traits like resilience, irritability, optimism that define them and are consistent throughout life.

In other words, whether you see the glass as half-empty or half-full will affect how you adapt to a new normal. And a patient may be diametrically opposite to how a doctor would respond to a diagnosis and choice of treatment. What is most important to the patient may not even be on the doctor's radar.

As Dr. Gordon H. Guyatt of McMaster University in Hamilton, Ontario, put it in an article in *The Mayo Clinic Proceedings*, "If the primary goal of therapy is to improve the way patients feel," assessing quality of life when making clinical decisions is essential.

Dr. Rainer said: "These days, patients have to be their own best advocates, well schooled on symptoms, disease states and treatment options, and use their physicians as colleagues. This can be quite a challenge for patients who still defer to their physicians. But it's no longer in a patient's best interests to say to the physician, 'You know what's best.' "