

EDITOR'S PAGE



Quality of Life: Do We Know What Patients Want?

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In the care of individual patients it is assumed that the patient and physician are always in agreement on what they want the end point(s) of therapy to be. The following two examples illustrate how differences can occur:

The first is that of an asymptomatic patient with moderately severe hypertension whose blood pressure is controlled with combined drug therapy. The physician is pleased because the target blood pressure is reached. The patient feels that he is receiving good care because his blood pressure is controlled, but he also notices the onset of insomnia, impotence and dizziness. He finds it difficult to continue playing golf because he feels dizzy each time he bends down to tee up the ball or mark it on the green. Unless these issues are communicated between the two, the life-style of the patient will be markedly compromised.

The second example concerns a very symptomatic patient with severe end-stage heart failure. In such a patient, we usually select therapy to prolong life (such as an angiotensin-converting enzyme [ACE] inhibitor or heart transplantation in appropriate patients). At our institution we have a protocol for an oral phosphodiesterase inhibitor in such patients. We know, however, that controlled trials with the oral phosphodiesterase inhibitors in chronic heart failure have shown increased mortality (1). Thus, the patient is faced with signing a consent form that indicates that the drug may improve symptoms but may also shorten life. Almost invariably, the patient will want to take the drug because as the quality of life approaches zero, the quantity of life becomes meaningless. The dictum to "do no harm" has been overridden by issues of improved quality of life.

Both of these examples are about quality of life, one of the most difficult things that we attempt to quantitate. There has been increasing interest in developing different ways to measure quality of life so that we can better judge the effects of therapeutic interventions. Examples include the Sickness Im-

pact Profile (2), dyspnea-fatigue rating (3), Nottingham Health Profile (4), Quality of Well Being Scale (4) and Minnesota Living with Heart Failure Questionnaire (5). The development of these instruments highlights the increasing realization that symptom control and quality of life are at least as important if not more so than quantity of life. With the severe time constraints imposed by our current health care system, it is going to be increasingly difficult to evaluate quality of life and keep this as a high profile discussion item in serial encounters.

Over the past few years, I have tried to be very sensitive to quality of life issues with individual patients. Some of the principles that have guided me are the following:

1. Determine a baseline quality of life by getting to know each patient. Appropriate questions can focus on the nature of their work and home life, hobbies and leisure time activities, sleep and eating habits, physical capabilities and stressful circumstances. I especially like the question: What things do you most like to do?

2. Find out what limitations have been imposed on them by their illness. A key question is: What things would you like to do, that you can no longer do because of your illness? I once had a patient declare that if he couldn't play golf, life was no longer worth living. Although this might seem like an absurd statement to some nongolfers, it rings very true to avid golfers.

3. Always attempt to address their current symptoms, even if they seem unrelated to the underlying problem. Do not ignore the patient's headache or sore feet, even if they seem unrelated to the episodic atrioventricular node reentrant tachycardia that is the cardiac problem.

4. Carefully evaluate the potential for side effects of medications or other therapies. Individual patients do not always spontaneously discuss common side effects of some drugs, such as dry cough, flushing or insomnia. It usually requires a direct question from the physician to elicit the side effect of impotence.

5. Attempt to directly improve the patient's quality of life.

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This attempt might include encouragement to take a desired trip, the suggestion that the patient could play nine holes of golf with a cart or reassurance that it is safe to fly in a plane. This attempt, where medically appropriate, should be to help patients participate in those things they like to do best. Reversal of physical deconditioning can be especially helpful.

6. Above all, be a sympathetic and compassionate listener. The process of talking things through is frequently therapeutic for the patient, especially where symptoms are concerned. Although you may not be able to completely relieve that chronic low back pain, an empathetic listener may be more helpful than the latest nonsteroidal anti-inflammatory drug.

In summary, a heightened appreciation of issues related to a patient's quality of life, will go a long way toward improving that quality. Years ago practitioners seemed to do this without the benefit of any wonder drugs. Surely, with the availability of

all the powerful therapeutic options that we have today, we should be able to do even better.

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