Glossary

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What is quality of life assessment and how is it currently measured?

The issue of quality of life has become increasingly prominent in both the popular press and medical literature. Quality of life assessment is a personal process. Any formal assessment (e.g., questionnaire), to be most valid, would have to simulate the way people think about their quality of life. We are constantly appraising our experiences and valuing the outcomes we observe. For example, if we get a salary increase and find that we have some greater financial stability, then this may enhance our sense of well-being. On the other hand, if we have to have surgery because we have a disease then our concern over that would effect our view of our life's quality. This constant processing of information is the essence of what a quality of life assessment is about.

What are some ways we deal with information and how is this standardized and reflected in medical literature?

If you have a functional bowel disorder such as IBS, your current symptoms or anticipated symptoms of pain or discomfort may cause you to restrict or modify your activities. You may notice that you have to carefully schedule your traveling so that a bathroom is accessible. Each of these experiences thrust themselves into your awareness and you catalog and describe them while you regularly monitor the intensity with which they occur. You can report how distressing your abdominal pain was today as compared to yesterday. At the same time, you can reflect on all of these events and measure their impact on you or the way you feel. These three cognitive (thinking or reasoning) processes – describing what is happening to you, measuring the intensity of these descriptive states, and choosing a preference for being in any of these states – are the essence of what is currently considered to be a quality of life assessment.

A fourth major activity we engage in is our tendency to combine different experiences so that some of these become more important to us than others. For example, you may ask someone about their quality of life, and they may say it is "lousy." You discover it is because of a specific reason. The reason often deals with some physical complaint. Thus, diarrhea or pain may become the focal issue that dominates the assessment of quality of life.

We also know that people who tend to react intensely to events also react in this manner when they are asked to assess their quality of life. How we cope with distress, in general, often is reflected in our appraisal of our quality of life.

Does quality of life assessment effect treatment options?

One of the most interesting characteristics of quality of life assessment is that it covers a broad range of issues and subject matter areas. It is legitimate to think about what would be an ideal outcome for a person and use that as a measure of quality of life or of the usefulness of a medical treatment. Quality of life assessment can be used as an indicator to compare two treatments and make decisions (about treatment options) in these terms. In effect, when this is done the patient's opinion becomes the central theme in

the decision making process. While this seems the obvious thing to do, it is not something that was done very much, prior the last 25 years or so.

The history of quality of life assessment in a medical context really only dates back to the early 1950s and 1960s, although the concept of pursuit of happiness has been with us since the time of Aristotle. Interestingly, it was Presidents Johnson and Eisenhower who referred to the quality of our existence as a measure to evaluate governmental programs, thereby initiating interest in quality of life assessment.

In the early to mid 1970s, a variety of assessment instruments were developed which reflected a patient's health status. This area of activity was then combined with an experimental procedure and the clinical trial (studies which provide large amounts of data to valid statistical information), and applied to evaluate the outcome of medical treatment.

One of the early experiments in this area was a study in which I was involved. It demonstrated a very important capability of a quality of life assessment – that it can lead to a change in medical treatment. In this study of people who had soft tissue sarcoma (malignant tumor), one group of patients were treated conservatively with removal of the tumor followed by radiation to the surgerized limb. Alternatively, the other group of patients had their limb amputated. The question we asked was which patient was better off?

What we found was that the groups were comparable. However, the surgeon who was involved with the trial felt that people whose limb was spared should be better off. Why weren't they? He raised questions and determined that changes had to be made in the radiation therapy, chemotherapy, and surgery they received. As a result (after these changes), it was possible to demonstrate that later patients actually improved in terms of functional outcome.

This study, which was performed more than 25 years ago, remains a significant demonstration of the power of a quality of life assessment. If the assessment is used in an appropriate way, it is possible to improve the quality of care.

Most often, quality of life assessments are used to describe outcome. This more standard procedure usually occurs after the treatment regimen has been established. Thus, most assessments catalog treatment outcomes and provide important patient education information. Within this context, a variety of assessment instruments have been developed.

Summary

In general, a quality of life assessment is one of the most important ways that a patient has to have his or her interest expressed in the design and selection of treatments.

You should be aware of this and ask your doctor about what he or she knows about the qualitative, or quality of life, consequence of any new treatment you are being asked to take. In this way you can become a powerful force in keeping the quality of life issues as a visible part of medical practice.

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