



A new quality of life questionnaire for patients with inflammatory bowel disease

NOT TOO long ago, inflammatory bowel disease was a severe disease with a poor prognosis. In an early study on children with Crohn's disease diagnosed between 1919 and 1965, the 20-year survival rate was 22% lower than expected.¹ During the 1960s and 1970s, the situation improved considerably. In a later study from Stockholm, the observed mortality was just 3% higher than expected in patients followed over a 20-year period.² The excess mortality was mainly related to surgery on severely ill patients during the first year after onset of disease. Similar figures have been published for ulcerative colitis. In recent years, mortality for inflammatory bowel disease has become so low that mere survival is no longer a major issue.

■ See Farmer et al, p. 35

Both diseases have an intermittent course with relapses and remissions. Treatment, whether surgical or medical, is aimed at breaking relapses and thus inducing remission. The results of treatment have improved significantly, and today we usually succeed in achieving this goal. The main problem now is not merely achieving remission but monitoring the patient during remission. Early detection of a patient's tendency to relapse can result in early action to avoid severe relapses. In the future, better maintenance therapy may keep patients in remission for longer periods of time.

The aim of remission monitoring is to provide that both disease and therapy interfere as little as possible with the patient's everyday life and general well-being. However, different patients need different treatment, and there is an increasing need to develop instruments that can assess the patient's everyday function and the level of well-being. These should also include an evaluation of the communication be-

tween patient and doctor.

To be useful, "quality of life" must adhere to the same standards as other scientific concepts. It must be clearly defined and measurable. In the current literature, the following concepts have been defined³: *general subjective quality of life*, the degree to which the individual is satisfied with everything in life; *means-specified subjective quality of life*, the degree to which the individual feels his or her needs are satisfied; *means-specified objective quality of life*, the degree to which the individual's needs are in fact satisfied; *health*, individual and society resources for good quality of life; and *disease or symptoms of disease*, impairment of quality of life by direct factors such as pain, nausea, and anxiety, or by indirect factors such as paralysis, reduced consciousness, and intellectual defects. The difference between means-specified subjective quality of life and means-specified objective quality of life is largely dependent on the individual's *level of aspiration*. This is variable and, particularly in patients with chronic diseases, depends on the nature of the symptoms and the character of the disease.

In this issue of the *Cleveland Clinic Journal of Medicine*, Farmer et al present an evaluation of a new quality of life questionnaire for patients with inflammatory bowel disease. The questionnaire consists mainly of questions that reflect general subjective quality of life in combination with health and disease assessments. Means-specified subjective and objective quality of life are more difficult to measure: the methods which have been used, such as linear analogue scales, have a low reliability.³ However, further refinement of Farmer et al's quality of life instrument should include an attempt to evaluate means-specified quality of life. The results of their study are nevertheless encouraging: by using univariate analysis, the authors were able to identify 18 questions that were valid and reliable for discriminating between various degrees of quality of life.

In the present study, Crohn's disease patients who had undergone surgery had the worst quality of life relative to the other disease subgroups. In Stockholm we recently performed a pilot study with a somewhat simplified quality of life questionnaire (unpublished data). In contrast to the results of Farmer et al, our postsurgical Crohn's disease patients scored better than did the non-surgical patients.

The divergent results of our survey and the present questionnaire may reflect the distinct difference in the treatment of inflammatory bowel disease between Europe and the United States. In Europe, we usually use steroids in lower doses and over shorter periods of time than in the United States, and we use surgery earlier in the course of the disease. The two survey results may therefore indicate that in Europe we undertreat the medical patients; they may also indicate that patients in the United States are referred to surgery too late.

Validated and tested quality of life questionnaires are important tools for patient management. Controlled trials are excellent for evaluation of isolated treatment events. However, for evaluation of long-term treatment strategies, particularly in chronic diseases, we must rely on instruments such as quality of life questionnaires.

GÖRAN HELLERS, MD, PhD
Chairman, Department of Surgery
Huddinge University Hospital
Karolinska Institute
Stockholm

REFERENCES

1. Weedon DD, Shorter RG, Ilstrup DM, Huizenga KA, Taylor WT. Crohn's disease and cancer. *N Engl J Med* 1973; **289**:1099-1102.
2. Hellers G. Crohn's disease in Stockholm County 1955-74. *Acta Chir Scand Suppl* 1979; **490**:1-84.
3. McDowell I, Newell C. Measuring health. A guide to rating scales and questionnaires. New York: Oxford University Press, 1987.

