



Original article

Objective assessment of quality of life following panproctocolectomy and ileostomy for ulcerative colitis

John Camilleri-Brennan, Robert JC Steele

University Department of Surgery and Molecular Oncology, Ninewells Hospital and Medical School, Dundee, UK

A panproctocolectomy and permanent ileostomy improves the quality of life of those suffering from ulcerative colitis. However, it is not known how the quality of life of patients who had this operation compares with that of the general population. The aim of this study was to measure the quality of life of these patients using a reliable and validated instrument, and to determine whether these patients enjoy a similar quality of life to the general population.

Forty-nine consecutive patients (31 males and 18 females, median age 49 years), who had a panproctocolectomy with a permanent ileostomy for ulcerative colitis in one of three hospitals in Tayside, UK from 1992–1997, participated in the study. The median number of months (range) post-surgery was 29 (12–72). Participants answered a well-validated generic questionnaire on health-related quality of life: the new SF-36 version 2.0 (SF-36II). The results were then compared with population norms of similar age and gender, derived from the Third Oxford Healthy Lifestyle Survey and published by the Health Services Research Unit of the University of Oxford.

The mean score difference between patient and population SF-36II scores (95% confidence intervals) were as follows: physical functioning (PF): –3.9 (–9.4, 1.6); role-physical (RP): –4.1 (–9.9, 1.7); role-emotional (RE): –0.1 (–5.6, 5.4); energy-vitality (EV): 8.2 (2.8–13.6); body pain (BP): 6.6 (0.3, 12.9); social functioning (SF): 3.7 (–2.7, 10.1); mental health (MH): 2.5 (–2.5, 7.5); general health perception (GHP): –1.8 (–7.6, 4.0).

Despite the fact that these patients underwent major surgery and have a permanent stoma, their quality of life as measured by the SF-36II was very similar to that of the general population.

Key words: Quality of life – Ulcerative colitis – Surgery – Panproctocolectomy – Ileostomy

Correspondence to: Mr John Camilleri-Brennan, University Department of Surgery and Molecular Oncology, Level 6, Ninewells Hospital and Medical School, Dundee DD1 9SY, UK. Tel: +44 1382 660111; Fax: +44 1382 641795; E-mail: johncbrennan@doctors.org.uk

Despite recent advances in surgery for ulcerative colitis, in particular the development of restorative surgical techniques, a panproctocolectomy and conventional (Brooke) ileostomy (PPC+I) is still considered by some to be the 'gold-standard' procedure.¹ Although the patient is left with a permanent, incontinent stoma, it is a safe operation with a low complication rate.

Quality of life is increasingly becoming an important outcome measure in surgery. It is a multidimensional construct, representing an individual's subjective perception of physical, social and psychological well-being, as well as satisfaction with the balance between disease control and adverse effects of treatment.² Measurement of quality of life and analysis of symptoms of patients who had PPC+I was done in a number of studies. In general, these studies have assessed aspects of quality of life such as performance status,^{3,4} patient satisfaction,^{3,5} psychological morbidity,⁶⁻⁸ and social function,³⁻⁸ using in most cases unvalidated questionnaires. The results have shown a high performance level and satisfaction with surgery in those who had a PPC+I. Using validated questionnaires, two studies showed that global quality of life scores in these patients were high.^{9,10} There was a marked improvement from the pre-operative scores,⁹ and the scores were similar to those obtained from patients who had a continent (Kock) ileostomy⁹ or a restorative proctocolectomy.^{9,10} However, a direct comparison of the quality of life of patients with a PPC+I to that of the general population has not been carried out. It is thus not known whether this curative operation for ulcerative colitis restores a patient's quality of life to that enjoyed by the general population.

The aims of this study were to measure the quality of life of these patients using a reliable and validated instrument, and to determine whether these patients enjoy a similar quality of life as the general population.

Patients and Methods

The subjects who were eligible for this study were patients who had a PPC+I for ulcerative colitis and who were more than 18 years old at the time of assessment. They had their operation in one of three hospitals in Tayside, UK, from January 1992 to July 1997. Sixty patients were identified. Six patients had left the region and could not be traced, whilst one had died 3 years after surgery. The remaining 53 patients were contacted and given a quality of life questionnaire, the SF-36 version 2 (SF-36II), to complete themselves. They were also asked to return the completed questionnaire by post in the stamped self-addressed envelope that had been provided.

The SF-36 originated in America from the Medical Outcomes Study.^{11,12} It measures subjective health status

or health-related quality of life, and has been designed to be self-administered. It consists of 36 items, measuring eight dimensions of health on multi-item scales. The eight dimensions measure physical functioning (PF), social functioning (SF), role limitations because of physical and emotional problems (RP and RE), mental health (MH), energy and vitality (EV), body pain (BP) and general health perception (GHP). The scoring scale ranges from 0 to 100, with lower scores indicating worse health. In addition, two summary scores have been derived for this instrument: the Physical Component Summary Score (PCS) and the Mental Component Summary Score (MCS). For this study we used the SF-36 version 2 (SF-36II),¹³ which has an improved layout, wording and scaling, as well as improved reliability over the original version of the SF-36.¹³⁻¹⁵

Population norms for the SF-36II have been produced from a large scale social survey, the Third Oxford Healthy Lifestyle Survey.^{14,15} This was carried out in four regions of the UK in 1997 and published by the Health Services Research Unit of the University of Oxford. The socio-demographic characteristics of the population sample in this social survey were shown to be very similar to the characteristics of the general UK population. Therefore, the quality of life data obtained from the survey are considered to be representative of the general UK population.

Demographic data and relevant medical information were obtained from the patients and their hospital case-notes. The Tayside Committee on Medical Research Ethics approved this study.

Statistical analysis

Patient scores for each quality of life dimension of the SF-36II as well as the summary scores (physical and mental) were computed using the methods recommended by the developers.^{13,16} These scores were then compared to the published scores of the general population of similar age and gender.^{14,15} The differences in mean scores of patients and the general population and 95% confidence intervals (CI) were then calculated for each dimension.

Results

A total of 49 patients, 31 males and 18 females, participated in the study. Four patients did not return the questionnaire, despite two reminders that were sent by post, 1 month apart. The median age (range) of the participants was 49 years (20-82 years). The median number of months (range) after surgery was 29 (12-72). No patient was on any steroid or immunosuppressive medication.

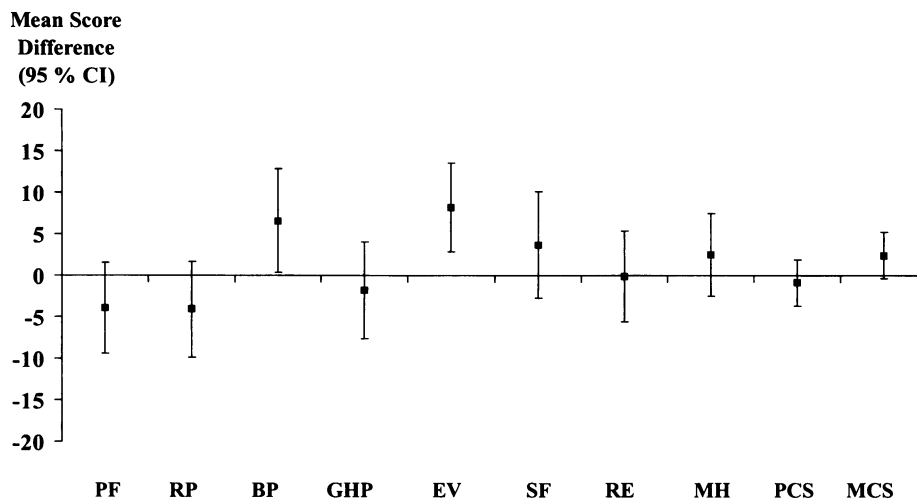


Figure 1 Difference in mean SF-36II scores and 95% CI between patients and general population, for all dimensions and summary scores. PF, physical function; RP, role limitations due to physical problems; EV, energy and vitality; BP, body pain; RE, role limitations due to emotional problems; SF, social function; MH, mental health; GHP, general health perception; PCS, physical component summary; MCS, mental component summary.

The difference in mean scores between patients and the general population is shown in Figure 1. The scores for most dimensions are similar except for the pain and the energy and vitality scores, which are higher for our patient group. There is no difference between the patient Physical and Mental Component Summary Scores and those derived from the general population.

Discussion

Measurement of quality of life is necessary in order to determine the impact of a disease and its treatment on an individual's well-being.² Formal quality of life studies on patients with a PPC+I have used mainly unvalidated, study-specific questionnaires or surveys. However, despite methodological limitations, patients seem to have a good performance status,^{3,4} and satisfaction with the operation tends to be high.^{3,5} The reported prevalence of psychological problems varied from 5–12%.^{6–8} These problems are usually the result of negative feelings of body image owing to the presence of the stoma. One study using the time trade-off technique and the sickness impact profile showed improved global quality of life scores after surgery when compared to the immediate pre-operative status.⁹ The scores in these patients with a PPC+I were high, similar to the scores obtained from patients who had a continent (Kock) ileostomy or a restorative proctocolectomy. Similarly, a study using a modified Inflammatory Bowel Disease Questionnaire showed no difference in quality of life

scores when patients with a restorative proctocolectomy and a PPC+I were compared.¹⁰

On the whole, these studies have shown that patients who undergo a PPC+I enjoy a good quality of life. However, they do not indicate clearly how quality of life compares with that of the general population. It is thus not known whether achieving a cure from ulcerative colitis, by means of major surgery and the creation of a permanent ileostomy, restores an individual's quality of life to the level of the general population.

In this study, we used the most recent and updated version of the SF-36 questionnaire, the SF-36II. It is a generic questionnaire, designed for comparing quality of life across patient populations and disease groups. Patient scores were compared to the scores obtained from the general UK population of similar age and gender.

The scores directly relating to physical well-being (physical functioning and role-physical) as well as the Physical Component Summary were similar to the general population. This implies that our patients were able to carry out their daily physical activities reasonably well, with little or no problems relating to their physical health. The score achieved for the energy and vitality dimension also indicates that following this operation, patients generally do not experience undue tiredness or fatigue when performing their daily routine activities. Pain scores were similarly high, implying that patients either suffered little or no bodily pain, or had only a few limitations due to pain.

The scores in the mental health and role-emotional dimensions, as well as in the social functioning dimensions,

were similar to the population scores. Thus, the psychological and social aspects of quality of life of patients who had a PPC+I are not different from the general population. General health perception scores were also similar. This means that patients with a PPC+I believe their personal health is as good as the general population and is unlikely to get worse.

Some studies, including a recent one from Sweden,¹⁷ showed that patients suffering from ulcerative colitis have marked physical, psychological and social problems which are directly related to the severity of their disease. The quality of life of these patients is low. In contrast, our study shows that surgery, by removing a patient's diseased colon and rectum, restores a patient's quality of life to normal. Thus, despite the presence of a permanent ileostomy, not only is quality of life good after surgery, but it is similar and in some ways better than that of the general population. The results of this study are useful in helping patients with ulcerative colitis make an informed decision regarding definitive surgery that will cure their disease.

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