World J. Surg. 10, 474–480, 1986

World Journal of Surgery

Factors Affecting Quality of Life with a Conventional Ileostomy

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Two hundred seventy-three patients with inflammatory bowel disease and permanent conventional ileostomies were surveyed to determine which factors affect the health and quality of life of the ileostomate. Physical and emotional health were considered good or excellent by 79% and 78%, respectively. Only a small number of patients (approximately 20%) felt they were more restricted with the ileostomy with regard to diet, clothing selection, leisure and work activities, and travel than they were preoperatively. Despite these restrictions, 74% stated they led normal, unrestricted lives; 23% experienced some restrictions and had some difficulties psychologically but were glad they had surgery. Only 3% regretted having surgery. Only one factor, function of the ileostomy, affected patients' physical and emotional well-being, ability to perform work and daily activities, and their overall outlook on life. Other factors such as age, sex, duration of the disease preoperatively, duration since surgery, and disease etiology and activity seemed to make no difference. Thus, it appears that the surgeon plays an important role in determining the well-being and quality of life of the conventional ileostomate.

There is no doubt that the life of the ileostomate has improved in the past 25 years [1]. The modifications in surgical technique described by Brooke [2] and Crile and Turnbull [3] have been critical in reducing morbidity and mortality. Advances in ostomy appliances and equipment have minimized the problems of leakage, odor, and skin irritation. Together they have given the ostomate good health and freedom to perform normal activities. Of equal importance has been the emergence of ostomy associations to provide education and support to the ostomate and his family. Public awareness has lessened the social stigma attached to an ileostomy.

While it is true that most patients adjust easily to their ileostomy, there are some who have difficulty coping with it. This may be because of physical or psychological problems. However, why one patient is satisfied and another one is dissatisfied is not always readily apparent. Thus, this study was undertaken to determine which factors are important in determining the health and quality of life of an ileostomate and his or her acceptance of an ileostomy.

Methods and Materials

Questionnaires were sent to 353 ileostomates registered in the Outpatient Department of the Cleveland Clinic. All had been seen within the past 3 years. Some had been seen because of problems relating to their ileostomies or recurrence of their disease. Others returned for routine postoperative or yearly visits. All questionnaires were sent out and returned by mail. Patients were given the option of remaining anonymous. Because "quality of life" is multifactorial, we chose to assess it in terms of the following components: physical well-being; emotional well-being; lifestyle, including diet, hobbies, sports, travel, and clothing selection; work status; and overall satisfaction with the ileostomy. Sexual function, although important, was not assessed because previous reports have addressed this issue [4].

Questions were designed so an objective response could be given. Analysis of data was done using chi-squared tests to test associations among factors affecting life with an ileostomy.

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Table 1. Physical well-being before and after surgery.

	Preoperatively	Postoperatively
Excellent	15 (5.5%)	81 (29.7%)
Good	34 (12.5%)	134 (49%)
Fair	41 (15%)	48 (18%)
Poor	183 (67%)	9 (3%)
No response	0 (0%)	1 (0.3%)
Total	273 (100%)	273 (100%)

Table 2. Emotional well-being before and after surgery.

	Preoperatively	Postoperatively
Excellent	22 (8%)	78 (28%)
Good	72 (26%)	130 (48%)
Fair	83 (31%)	40 (15%)
Poor	90 (33%)	20 (7%)
No response	6 (2%)	5 (2%)
Total	273 (100%)	273 (100%)

Table 3. Time lost from routine activities before and after surgery.

	Preoperatively	Postoperatively
<1 week	41 (15%)	106 (39%)
1 week–3 months	112 (41%)	67 (24.5%)
>3 months	97 (36%)	67 (24.5%)
No response	23 (8%)	33 (12%)
Total	273 (100%)	273 (100%)

Table 4. Work status before and after surgery.

	Preoperatively	Postoperatively
Full time job/student	157 (58%)	132 (49%)
Housewife	43 (16%)	36 (13%)
Part-time job	23 (8%)	31 (11%)
Retired or unemployed (unrelated to illness)	20 (7%)	28 (10%)
Disabled (due to illness)	26 (10%)	28 (10%)
No response	4 (1%)	18 (7%)
Total	273 (100%)	273 (100%)

Results

Three hundred twenty-two patients answered the questionnaire. Forty-nine patients were excluded because they had temporary loop ileostomies or a disease other than inflammatory bowel disease. Thus, this report is an analysis of the replies of 273 patients, all of whom had ulcerative colitis or Crohn's disease and had permanent ileostomies.

There were 127 (47%) males and 146 (53%) females. The average age was 43 years (range 12 to 85 years). One hundred and twenty-one (44%) patients had ulcerative colitis and 152 (56%) had Crohn's disease. Twenty-two (8%) of the patients stated they had an unhealed perineal wound and 30 (11%) stated they had other symptoms related to their primary disease. Twenty-eight (18%) with Crohn's disease judged their disease to be active at the time of answering the questionnaire.

Symptoms had been present preoperatively for less than 1 year in 55 (20%) patients, from 1 to 5 years in 94 (34%) patients, and more than 5 years in 124 (45%) patients. Two hundred ten (77%) patients had a total proctocolectomy, while 63 (23%) had an abdominal colectomy with preservation of the rectal stump. Surgery had been done an average of 7 years previously (range 4 months to 48 years). The ileostomy was considered to function perfectly by 95 (35%) patients. One hundred fifty-five (57%) patients stated the ileostomy functioned satisfactorily, but they had some difficulties with leakage or skin problems. Twenty (7%) felt the ileostomy functioned poorly.

Preoperative Versus Postoperative Health and Quality of Life

Tables 1 and 2 document physical and emotional well-being both pre- and postoperatively. Comparison of patients' responses indicated that the majority considered their health to be improved. This was also reflected by the fact that patients missed less time from their routine activities postoperatively (Table 3).

Patient work status was categorized according to whether they: (a) worked or attended school full time; (b) worked part time; (c) were housewives; (d) were retired or unemployed (unrelated to their illness); or (e) were disabled because of their illness or ileostomy (Table 4). Preoperatively, 58% of patients worked or attended school full time. Of these, 36% stated their illness prevented them from pursuing a career of their choice and 23% felt they missed normal career promotions because of it. Postoperatively, 64% of patients maintained the same job status as preoperatively. Thirteen percent were working more and 22% were working less. Whether these changes were due to their illness or to other factors could not be determined.

Of the 58% of patients who worked or attended school full time preoperatively, almost one-third had been promoted in their jobs postoperatively and 20% of these patients attributed their success to their improved health. Only 15% had been demoted or lost their jobs, but nearly half (48%) of these felt that it was because of the ileostomy. The rest of the patients had stayed at the same job (31%) or changed jobs (15%), unrelated to their ileostomy. Eleven percent did not answer this part of the questionnaire.

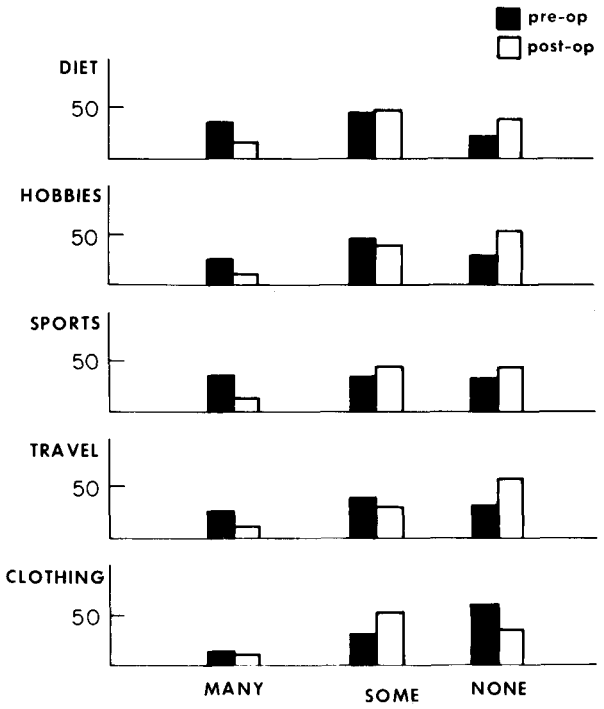

Fig. 1. Restrictions in activities and lifestyle before and after surgery (in % patients).

Restrictions in diet and clothing selection, as well as activities (hobbies, sports, and travel), were encountered by patients whether they suffered from their disease or had an ileostomy (Fig. 1). However, with the exception of clothing selection, patients were less restricted in these areas after surgery (Table 5).

Factors Affecting Health and Quality of Life

Seven factors were assessed with regard to their effects on the patients' health and their perception of their quality of life. These factors were: age; sex; length of time symptoms were present preoperatively; etiology of the disease (i.e., ulcerative colitis or Crohn's disease); disease activity (i.e., active or inactive Crohn's disease); length of time since surgery; and patient's perception of ileostomy function.

Of these, only function of the ileostomy had any effect on patients' assessment of their emotional and physical well-being and on their work status and amount of time lost from routine activities (Tables 6–9). (Age and sex were significant variables in terms of work status, but this is to be expected and unrelated to the disease.) Although the number of patients in some groups is too small to allow formal statistical testing for associations, differences can be noted. For example, few patients with poorly functioning ileostomies considered their health to be excellent and half considered their health to be fair or poor. This trend was reversed if the ileostomy functioned perfectly. Ileostomy function also appeared to have a marked effect on patient's capacity to work and ability to perform routine activities.

Overall Satisfaction

In assessing their overall satisfaction, 200 (73%) patients stated they were "glad they had surgery and felt they led normal, unrestricted lives." Sixty-one (22%) stated they were "glad they had surgery but felt restricted by the ileostomy or had difficulties adjusting to it." Only 8 patients (3%) stated they "regretted having surgery and would prefer living with their disease."

In determining what factors affected this assessment, again, age and sex of the patients, disease etiology and activity, and length of time symptoms were present preoperatively and made no difference. Only function of the ileostomy was important (Table 10). Since only a few patients had poorly functioning ileostomies, the differences were not statistically significant. Notwithstanding that, however, there is a readily apparent difference between 88% patients with a perfectly functioning ileostomy being happy with the result compared with only 17% patients with a poorly functioning ileostomy. Virtually no patient regretted having surgery and an ileostomy, provided the ileostomy functioned satisfactorily. Seventeen percent of patients with poorly functioning ileostomies regretted having surgery.

Discussion

This study confirmed the impression that most ileostomates are in good health and are generally satisfied with their ileostomies. As one would expect, physical well-being is markedly improved over the preoperative state of health. Postoperatively, almost 80% of patients considered their health to be good or excellent. This was particularly gratifying considering that over half of this group of patients have Crohn's disease and are at risk to develop recurrent disease. The emotional health of this group was also good and only a small number had psychological problems adjusting to their stomas. In fact, fewer patients had difficulties coping with the ileostomy than with their chronic disease (i.e., 8% postoperatively had poor emotional health compared with 34% preoperatively). Reports documenting good health in ileostomates have been published previously. Morowitz and Kirsner [5], in a survey of 1,803 ileostomates, found that 88% considered their health to be improved or

Table 5. Restrictions in diet, clothing selection, hobbies, sports, and travel postoperatively versus preoperatively.

Restrictions	Diet	Clothing selection	Hobbies	Sports	Travel
Same	91 (33%)	125 (46%)	114 (42%)	107 (39%)	97 (36%)
Less	120 (44%)	37 (14%)	107 (39%)	101 (37%)	120 (44%)
More	57 (21%)	88 (32%)	44 (16%)	50 (18%)	43 (15%)
No response	5 (2%)	23 (8%)	8 (3%)	15 (6%)	13 (5%)
Total	273 (100%)	273 (100%)	273 (100%)	273 (100%)	273 (100%)

Table 6. Effect of ileostomy function on physical well-being.

Physical well-being	Ileostomy function		
	Perfect	Satisfactory	Poor
Excellent	44 (46%)	34 (22%)	3 (16%)
Good	41 (43%)	84 (54%)	7 (37%)
Fair	8 (8%)	33 (21%)	6 (32%)
Poor	2 (2%)	4 (3%)	3 (16%)
Total	95 (100%)	155 (100%)	19 (100%)

Table 7. Effect of ileostomy function on emotional well-being.

Emotional well-being	Ileostomy function		
	Perfect	Satisfactory	Poor
Excellent	44 (47%)	34 (22%)	0 (0%)
Good	40 (43%)	79 (52%)	8 (42%)
Fair	5 (5.5%)	28 (18%)	7 (37%)
Poor	4 (4.5%)	12 (8%)	4 (21%)
Total	93 (100%)	153 (100%)	19 (100%)

Table 8. Effect of ileostomy function on work status.

Work status	Ileostomy function		
	Perfect	Satisfactory	Poor
Full time	51 (58%)	73 (50%)	5 (26%)
Housewife	11 (12.5%)	20 (14%)	5 (26%)
Part time	11 (12.5%)	18 (12%)	2 (11%)
Unemployed	11 (12.5%)	14 (10%)	3 (16%)
Disabled	4 (4.5%)	20 (14%)	4 (21%)
Total	88 (100%)	145 (100%)	19 (100%)

Table 9. Effect of ileostomy function on routine activities.

Time lost from routine activities	Ileostomy function		
	Perfect	Satisfactory	Poor
<1 week	45 (52%)	56 (41%)	4 (27%)
1 week–3 months	18 (21%)	46 (34%)	2 (13%)
>3 months	23 (27%)	34 (25%)	9 (60%)
Total	86 (100%)	136 (100%)	15 (100%)

greatly improved following surgery. Similarly, Roy et al. [6] found that 89% of ileostomates were in good or excellent health.

Table 10. Effect of ileostomy function on overall assessment.

Assessment	Ileostomy function		
	Perfect	Satisfactory	Poor
Pleased	84 (88%)	113 (74%)	3 (17%)
Satisfied	10 (11%)	36 (23%)	12 (66%)
Unhappy	1 (1%)	4 (3%)	3 (17%)
Total	95 (100%)	153 (100%)	18 (100%)

It was disappointing to find that despite the improvement in health, the percentage of patients disabled postoperatively did not differ from that preoperatively. However, whether their disability was due to the ileostomy alone, or to related medical causes could not be determined. It seemed, though, that Crohn's disease, particularly active disease, and a poorly functioning ileostomy increased the risk of the patient being disabled. Surgery also appeared to have virtually no effect on the percentage of people working. However, if patients did work, their work capability seemed to improve postoperatively in that many attributed promotions and job successes to improvement in health, whereas preoperatively they felt they missed career opportunities or promotions because of their illness.

It is to be expected that the ileostomy may cause some restrictions in lifestyle. However, the fact that 74% of patients felt that they led normal lives suggests that in most cases only minor adjustments in lifestyle are required. Furthermore, the lifestyle of most patients was improved over that of the preoperative state. About 40% of patients felt less restricted and only approximately 20% felt more restricted by the ileostomy than by their disease. The only exception was with regard to clothing selection for which more patients encountered restrictions. Restrictions in sports, particularly swimming, have been documented previously by Bone and Sorensen [7]. Roy et al. [6] reported that one-third of ileostomates surveyed had dietary restrictions and only one-half of patients participated in sports. However, only 17% had discontinued sports because of the ileostomy.

Notwithstanding the restrictions incurred with the conventional ileostomy, most patients had a

positive attitude toward their surgery and their life with an ileostomy. Seventy-four percent of patients endorsed the surgery without reservation while only 3% of patients regretted having surgery. Other series have reported equally good results. In the series of Bone and Sorensen [7], 94% of patients stated they felt normal. In the series reported by Roy et al. [6], 92% of patients were well adapted to their stomas and 69% stated they led normal lives. This underscores the fact that while alternative procedures such as the ileorectal anastomosis, continent ileostomy, and pelvic pouch and ileoanal anastomosis procedures are available, a conventional ileostomy is still a well-accepted operation in which good health and good quality of life can be achieved. Given that good health and a normal lifestyle with a conventional ileostomy are possible, every attempt should be made to achieve this. This study suggests that the surgeon plays a critical role in this regard, in that ileostomy function was the only variable that seemed to affect the outcome. Not only did it affect patients' perception of their health but also their work status and their overall assessment of their quality of life. No other factor was significant. Morowitz and Kirsner [5] previously reported that the duration of time that symptoms were present preoperatively was significant. They found that the patient who had symptoms for a longer period of time preoperatively accepted the ileostomy better. This was not found in our study.

Since ileostomy function is so critical, it behooves the surgeon to create a well-constructed and well-functioning ileostomy. Others have reported that surgical technical errors are the most common reasons for ileostomy revisions. In Goligher's review [1] of 96 ileostomy revisions, the indication was improper placement in 40. Taylor et al. [8] also found that faulty construction was the most common cause for revision. In this group, there were avoidable technical errors made, most significantly in 2 patients who had multiple abdominal scars that precluded proper siting. In 2 patients the problem was mucus discharge from loop-end ileostomies. In the other patients, however, there were factors beyond the surgeon's control. One patient had peristomal skin problems, 1 had high ileostomy outputs secondary to short gut syndrome, and 1 was grossly obese. Thus, while most problems are avoidable, it appears there is an occasional patient in whom ileostomy function is not optimal.

Résumé

Deux cent soixante-treize malades qui avaient présenté une affection inflammatoire intestinale et subi une iléostomie classique définitive ont donné lieu à une étude dont le but fut de déterminer les facteurs susceptibles d'affecter leur santé et la qualité de leur survie. La santé physique et psychologique de ces sujets a pu être considéré comme bonne et excellente dans respectivement 79 et 78% des cas. C'est seulement un petit nombre de patients (environ 20%) qui ont dit éprouver quelques réserves à propos du régime alimentaire, du choix des vêtements, de leurs activités de repos et de travail, de leur capacité de voyager et ce, par rapport à leur vie antérieure. En dépit de ces réserves 74% ont affirmé qu'ils avaient une vie normale, 23% qu'ils éprouvaient quelques inconvénients en particulier des difficultés psychologiques mais qu'ils étaient satisfaits de leur opération. Seulement 3% des malades ont regretté d' avoir été opérés. Un seul facteur, le fonctionnement de l'iléostomie, a paru affecter la vie physique et psychologique, l'aptitude à travailler et à accomplir les activités quotidiennes ainsi que le comportement général dans la vie. Les autres facteurs tels que l'âge, le sexe, la durée de la maladie avant l'intervention, le temps écoulé depuis l'opération, l'étiologie et l'intensité de la maladie n'ont semblé jouer aucun rôle. En conséquence le chirurgien joue un rôle important dans la vie du patient d'où la nécessité d'adopter la meilleure technique pour constituer une iléostomie de bonne qualité fonctionnelle.

Resumen

Doscientos setenta y tres pacientes con enfermedad inflamatoria del intestino e ileostomías convencionales permanentes fueron investigados para determinar qué factores afectan la salud y la calidad de la vida del paciente ileostomizado. La salud física y emocional fueron consideradas buena o excelente en 79% y 78% respectivamente. Sólo un número reducido de pacientes (aproximadamente 20%) consideró que se hallaban más restringidos por la ileostomía en cuanto a dieta, selección de sus ropas, actividades de trabajo, recreación y viajes, en comparación con su estado preoperatorio. A pesar de estas restricciones, 74% opinaron que llevaban vidas normales y no limitadas; 23% experimentaron restricciones y algunas dificultades psicológicas, pero se encontraban a gusto de haberse sometido a la cirugía. Sólo 3% lamentaban haber sido operados. Apenas un factor, el funcionamiento de la ileostomía, afectó el bienestar físico y emocional, la capacidad para realizar trabajo, la actividad diaria y la actitud general ante la vida. Otros factores tales como edad, sexo, duración preoperatoria de la enfermedad, duración de la enfermedad desde la cirugía y la etiología y actividad de la enfermedad, no parecieron tener influencia. Por consiguiente, parece evidente que el

cirujano juega un papel importante en cuanto a determinar el bienestar y la calidad de la vida del paciente con ileostomía convencional.

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Invited Commentary

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McLeod and colleagues from the Cleveland Clinic have carefully reviewed 273 patients with permanent ileostomies. Their review has confirmed that excision of the colon with formation of a permanent ileostomy is an excellent operation; the majority of patients adapt well to their new lifestyle and feel that the operation has been worthwhile. The benefits considerably outweigh the costs. This report emphasizes the importance of good surgery. The stoma must be properly constructed and sited. Problems with the stoma are the most common causes of restricted lifestyle after surgery; the physical status predicates the social and emotional outcome.

E.J.C. Lubbers of Nijmegen, Netherlands, and I in 1984 reviewed 102 patients on whom we had performed permanent Brooke-style ileostomies between 1970 and 1981 [1]. Our results were similar to this study, over the period of review to 1984. Thirty-three of the 102 patients developed some technical problem with their ileostomy that required surgical correction. The complications recurred at any time over the 14 years following surgery, emphasizing again the importance of long-term surveillance of ileostomates.

Kennedy and his colleagues from Oxford [2] reviewed the physical, social, and emotional health of 51 ileostomates. Using personality inventories they surveyed the physiologic, psychologic, and behavioral status of their patients; they found psychological abnormalities were minor. Their female patients had similar personality characteristics to a control population; however, their male patients tended to be more introverted and have significantly lower scores on a psychoticism scale. This fits with the greater defensiveness of male patients at clinical interviews after surgery and suggests that some degree of stigmatism of male ileostomates may occur. There was little evidence of physical impairment of their patients' sexual activity, but psychological problems associated with sexual activity were not unusual.

McLeod and colleagues report their ileostomates work well and their daily activity and overall outlook on life are good. Return to work following ileostomy has been reviewed in the United Kingdom by Whates and Irving who tested the experience of 1,033 members of the Ileostomy Association of Great Britain and Ireland. The majority of their patients resumed work with the same employer and in the same post after surgery. Only a small percentage of ileostomates in the United Kingdom had difficulty gaining or resuming employment after surgery. Indeed 5.7% of their patients began work for the first time after surgery, indicating the improved health and psychological status that surgery had given them. In contradistinction to the present series, Whates and Irving report that, once established in employment, successful career advancement was possible for ileostomates. An ileostomy seems to be no barrier to a very successful return to work in nearly all careers in the United Kingdom and is accomplished by the majority of patients without much difficulty.

The major message of this article is that while ileorectal anastomosis, continent ileostomies, and intra-abdominal pouchostomies are available, a conventional spout ileostomy is an acceptable operation after which a good quality of social and