

# MEDICAL PRACTICE

## Contemporary Themes

### Aftermath of Surgery for Anorectal Cancer

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#### Introduction

It has been estimated that there are over 100,000 patients with a permanent colostomy in Great Britain.<sup>1</sup> In 1957 and 1958 editorials in the *B.M.J.*<sup>2, 3</sup> asked "How do these people fare?" and emphasized that the problem of colostomy management is of profound importance for many. Nevertheless, since the major postwar reforms of 1945-50 there has apparently been no comprehensive study of the long-term effects of permanent colostomy in Britain. We have had considerable experience with colostomy patients in a hospital environment but felt that the long-term effects of a colostomy were probably underestimated by many clinicians and by those concerned with the domiciliary health and welfare services. The present study was undertaken to find out the effects of a permanent colostomy in daily life and to define areas of unmet need which could be attributed to the colostomy.

#### Methodology

All patients were interviewed twice, once in the outpatient department, at which each patient had a thorough physical examination, and once in their homes. Care was taken that the interviewer always visited patients who were unknown to him. The questions related to daily activities and leisure, and patients were also asked about hospital experience and utilization of medical care and social services.

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In both interviews questions were asked about diet, bowel function, and colostomy management. Despite the time lag between the two interviews the answers given showed a high degree of consistency. The questions were designed so far as possible to elicit a positive or negative response; however, volunteered comments were encouraged and coded. No one refused to answer any question. The hospital records of these patients were analysed for details of the preoperative features, mode of referral and admission to hospital, operative findings, and morbidity. Date and cause of death were also recorded where relevant so that calculations of survival rates could be made.

#### Results and Comments

##### CHARACTERISTICS OF PATIENTS STUDIED

The study included all patients in whom anorectal cancer was diagnosed between 1 February 1962 and 31 January 1969 and who were admitted to the care of surgical firm III at St. Thomas's Hospital or Mr. Ungley and his colleagues at Southend General Hospital (Table I). Fifty-five men and 28 women had colostomy operations, and 15 men and 23 women had restorative operations. The average age at operation for the men was 61.8 years, with a range of 48 years. Fifty-three

TABLE I—Numbers of Persons with Anorectal Cancer 1962-9

Hospital	Initial Population			Alive		
	Male	Female	Total	Male	Female	Total
St. Thomas's ..	102	80	182	53*	41*	94
Southend ..	65	67	132	18	12	30
Total ..	167	147	314	71*	53*	124

\*One male and two female patients were not traced. One female died between the home visit and the hospital appointment—that is, social follow-up: 70 men, 51 women interviewed; medical follow-up: 70 men, 50 women interviewed.

were married and living with their wives, five were single, and the rest were widowed or divorced. Eleven men lived alone, of whom nearly half were of pensionable age.

For women the average age at operation was 63 years, with a range of 40 years. Thirty were married and living with their husbands, five were single, and the rest were widowed or divorced. Fourteen women lived alone, more than three-quarters of whom were of pensionable age.

The patients were grouped into three social classes.\* Forty-two per cent. were non-manual, 30% were manual, and 26% were in social class III manual. Three patients were unclassified owing to insufficient data.

#### CONVALESCENCE

Seventy patients in this study, of whom more than three-quarters had a colostomy, spent some time in a convalescent home after leaving hospital. The most common dissatisfactions were inadequate hotel facilities, such as poor food, too many rules, and too little autonomy.

Others found the transition from considerable dependency on hospital staff to a state approaching self care too sudden. They felt that they were given too little help and advice with appliances by convalescent home staff. Another criticism directed at one home was that patients with colostomies were segregated from other patients at mealtimes. Nevertheless, many patients in this study found their stay in a convalescent home beneficial.

#### HOUSING

Substandard housing tends to make colostomy management more difficult for the "poorer" classes,<sup>4</sup> and good facilities for hygiene such as indoor lavatories, baths, and hot water assume a high priority for colostomy patients. On the whole there was little difference between the standard of housing found in the present study and that of the London and Essex area generally,<sup>5</sup> except that more of our patients had their own baths.

Nevertheless, 28 homes of colostomy patients (34%) lacked at least one and sometimes two or three basic amenities. It is not always sufficient to have an amenity—it must be usable. One woman in London had a fixed bath that was unusable because the water would not flow away. Sometimes the bath filled with waste from those who lived above her. In addition, her basement, containing her bathroom, kitchen, and one bedroom, flooded several times last winter to a depth of two to three feet (60 to 90 cm). She said that her landlord was unsympathetic and that the local authority said they were unable to condemn her basement as "unfit" because if they did so they would have to condemn many other houses in the area, and rehousing that many people was impossible.

A recent study<sup>6a</sup> has shown that in allocating housing on preferential health grounds local authorities take a narrower view of health hazard than is suggested as reasonable in the present study. We found five patients who had been rehoused since their operations, but 18 were still waiting.

#### EMPLOYMENT

Almost half the men in the present study were gainfully employed when interviewed. Twenty-four had retired from work before they became ill, of whom three, being near pensionable age at the time of operation, had been "forced" to retire early. Two were unemployed and actively seeking work and 13 were "off sick", of whom six had not returned to work since the operation. Thus they had been out of hospital and unfit for work for at least six months.

\*Based on the 6 occupational groups of the Registrar General 1966; social classes I, II, IIIN.M., IIIM, IV, and V.

Twenty-seven of the 31 men gainfully employed had a colostomy. Six of these colostomy patients (22%) felt unable to work full time as a result of the operation. Twelve could not meet the full demands of their old jobs and had arrived at an informal arrangement with their colleagues so that activities such as heavy lifting were done by someone else. Six men found return to their previous employment impossible either because the work was unsuitable or because the job was not held for them. The resultant change of employment had in all cases meant a substantial drop in income. One man had been registered disabled as a result of the hyperactivity of his colostomy. Thus 89% of male colostomy patients gainfully employed at the time of interview had changed their work habits in some way as a result of the operation. Of the four men who had restorative surgery one was working modified hours and two had sustained a reduction of income because their operation had necessitated a change of employment. Unlike the colostomy patients all four were physically capable of meeting the full requirements of their jobs.

At the time of the original surgery patients with a colostomy were off work longer than those without. For colostomy patients the mean time off work was 31.1 weeks (range 118 weeks, median 14.5 weeks). Forty-seven per cent. of the colostomy patients had returned to work 12 weeks after surgery, and 74% 24 weeks after surgery. Those who had restorative surgery had a mean time off work of 18.5 weeks (range 49 weeks, median 6.5 weeks). Comparison with this group is difficult as there were only 10 patients, but half of these had returned to work after only eight weeks "off sick," the rest being fairly evenly spread over the year. There appears to be no correlation between time "off sick" after surgery and social class.

As only a few women were involved (only 13 were employed at the time of interview, 3 full time and 10 part time), and as it is so difficult to assess the time at which full household duties are resumed, an analysis of women's employment and time "off sick" was not attempted.

#### Factors Affecting Colostomy Activity

##### NUMBER OF ACTIONS DAILY

In Britain the most commonly advocated method of colostomy control is natural evacuation.<sup>6-9</sup> This means that by judicious dietary restrictions, controlled fluid intake, and the use of medications the colostomy may come to evacuate once or twice daily at predictable times. Nevertheless, until 1964 there was apparently no quantitative assessment of this method of control.<sup>10</sup> Some surgeons in this country, and most in America, teach colostomy irrigation as the method of choice to achieve colostomy control. In Southend some patients were taught how to perform colostomy irrigations, but all patients in London were taught methods of natural evacuation.

When interviewed most colostomy patients were found to be using natural evacuation methods of control. Thirty-six (46%) of these people had one or two colostomy actions a day (see Table II). Twelve patients reported continuous diarrhoea and 15 had more than five colostomy actions daily. Thus 36% of patients using natural evacuation methods appeared to be unable to control their colostomies. This corresponds closely to the results obtained by Grier *et al.*<sup>10</sup>; this is surprising

TABLE II—Number of Colostomy Actions Daily (Natural Evacuation)

No. of Bowel Actions	Grier <i>et al.</i> <sup>10</sup>		Present Sample	
	No.	%	No.	%
0-1 .. .. .	7	14	13	17
2 .. .. .	12	24	23	29
3-4 .. .. .	15	30	15	19
≥5 .. .. .	16	32	27	36
Total ..	50	100	78	100

because their patients were specially selected to obtain optimum results for this method, whereas this was not true of the present study.

The five colostomy patients who were found to be using regular irrigation as a method of colostomy control form too small a group for analysis. Many of the other patients had found the irrigation procedure so distasteful that they had discontinued it. One man living near Southend, despite the fact that he irrigated daily and could not remember having an "accident," was so afraid of accidental spillage and odour that he had never left home since his operation.

#### DIET

Most patients were found to regard restriction of two foods as within the limits of a "normal diet." Therefore no distinction has been made between those with no dietary restrictions and those with only one or two. "Restricted quantities" is almost the same as a "normal diet," as people on this regimen ate everything but habitually restricted the quantities of certain foods. Less than half of the colostomy patients ate a normal diet, compared with almost three-quarters of those without a colostomy (Table III). Fourteen per cent. of the colostomy patients avoided six or more foods (some listed 12 and 13 foods avoided), compared with 2% of the other group. Those who would normally have eaten a midday meal at work in the canteen now took sandwiches. Others mentioned that they no longer ate out much or visited friends for meals because their diet made it too difficult. On the other hand, there were those who said that they enjoyed, for example, the firm's annual dinner, and regarded an overactive colostomy next day as a fair price.

TABLE III—Dietary Restrictions

No. of Foods Not Eaten	Colostomy		No Colostomy	
	No.	%	No.	%
0-2 (normal) .. ..	39	47	28	74
3-5 .. ..	26	31	5	13
≥6 .. ..	12	14	1	2
Restricted quantity ..	6	8	4	11
Total .. ..	83	100	38	100

Scoring: 1 point for each item of food excluded from the diet; 3 points for grouped foods—for example, "all fruit," "all salads"; 1 point for alcohol; and 1 point for beer (beer is widely acknowledged to have a particularly potent effect, causing colostomy hyperactivity).

A colostomy is not the only factor influencing dietary restriction. Social class seems to be an important influence. Thirty-one per cent. of both the non-manual classes and social class III manual workers, compared with 54% of the manual classes, ate a diet restricted by more than three items. Age was found to exert only a small influence; 33% of those under pensionable age reported three or more dietary restrictions compared with 40% over pensionable age.

#### MEDICATION

There are drugs of two basic categories which may be taken by

TABLE IV—Medications

Frequency of Medication	Patients		No. with 5 or more Bowel Actions Daily	
	No.	%	No.	%
Regular medication (at least once a week)	24	29	10	36
Occasional medication (less than once a week)	33	40	9	32
No medication .. ..	26	31	9	32
Total .. ..	83	100	28	100

patients to inhibit colostomy activity: firstly, those which inhibit colonic peristalsis and, secondly, those which increase the bulk of the stool, making it less fluid. We found that 31% of our patients had never taken any form of colostomy-controlling medication since they left hospital. The rest took medication occasionally or regularly. The number of people taking medication bore little relation to daily colostomy activity (Table IV).

#### APPLIANCES

Nearly half of our patients were using polyethylene bags, while the rest were using a belt and dressing, findings similar to those of Grier *et al.*<sup>10</sup> However, 33 patients had changed their appliances since leaving hospital, some having merely adapted the belt to make it more comfortable, but others having changed to a different design of belt altogether. Sixteen patients had changed from the belt and dressing with which they left hospital to an appliance incorporating a disposable polyethylene bag. Those in greatest need of a bag because of frequent, unpredictable bowel actions were no more likely than anyone else to possess such an appliance; indeed, they seemed less likely to be wearing a bag (Table V).

TABLE V—Appliances

Type of Appliance	Patients		No. with 5 or more Bowel Actions Daily	
	No.	%	No.	%
Disposable bags ..	40	48	8	29
Belts and dressings ..	43	52	20	71
Total .. ..	83	100	28	100

Thus of 28 patients with frequent colostomy actions only 10 took regular medication and 8 wore a colostomy bag. In these cases there appeared to be no reason why these people should not be getting better care except for a lack of communication between the patient and the health and social services.

#### Some Effects of Anorectal Cancer Surgery

##### URINARY FUNCTION

In the present study 18 men and two women had postoperative urinary retention for which further surgery was necessary in the case of 11 of the men.<sup>11</sup> After discharge from hospital half of the men and over a third of the women complained of urinary troubles such as frequency of micturition, urgency, or dysuria. Altered bladder sensation—that is, an inability to tell if the bladder was full or empty—was reported by 18 men and 6 women, while difficulty in voiding urine was experienced by 31 men and 5 women.

##### PHANTOM RECTUM

The phenomenon of "phantom rectum" was reported by 45 patients (56%). A further 10 patients complained of troublesome tenderness of the perineum. Physical examination showed that these patients probably had some residual infection or sinus in the perineum or possibly recurrence of the cancer.

##### SEXUAL FUNCTION

Of the 70 men interviewed in the present study 68 stated that they were heterosexual and two homosexual. Sixty-three of the former said that they enjoyed an active sex life before operation but fewer than half of them were still doing so afterwards

(Table VI). Of the 31 men who were impotent postoperatively 29 had a colostomy. Diminished sexual activity was reported by 15 colostomy patients and four who underwent restorative surgery (Table VII). Comparison with Kinsey's figures for American men<sup>12</sup> is difficult because of the small numbers in the present study in the relevant age groups. However, he found that 18% of men at the age of 60 were impotent and 27% at 70; 54% of our male patients were impotent after surgery in both of these age groups. Despite the doubt cast on Kinsey's figures because of his methodology this comparison must indicate a high degree of sexual dysfunction after surgery and especially colostomy operations.

TABLE VI—Sexual Activity

Degree of Activity after Surgery	Present Sample		Sutherland <i>et al.</i> <sup>11</sup>	
	No.	%	No.	%
Active .. ..	29	46	12	41
Impotent .. ..	31	49	14	48
Don't know .. ..	3	5		
Total ..	63	100	29	100

TABLE VII—Diminished Sexual Activity Postoperatively

Degree of Activity	Present Sample		Grier <i>et al.</i> <sup>10*</sup>	Druss <i>et al.</i> <sup>13</sup>
	No.	%	%	%
Normal .. ..	10	34	55	45
Diminished† .. ..	19	66	24	41
Total ..	29	100		

\*It is not clear from the reports if these figures relate to the whole sample or merely to those who were sexually active.

†Includes a change in the present study from intercourse 2.06 per week preoperatively to 1.12 per week postoperatively. Also those who were unable to ejaculate or experience orgasm postoperatively.

In many cases this change in sexual activity threatened the stability of the marriage. One family from social class I was found to be so close to a break-up that the husband asked the interviewer to talk to his wife and explain that his affection for her had not diminished but that owing to damage of the nerves at operation he was impotent. Some people reported embarrassment at wearing a colostomy appliance during intercourse, and one man was considerably inhibited by the fact that his colostomy always worked at this time.

Of the two homosexuals interviewed one described himself as asexual, having ceased sexual activity some years before the operation. The other described a social life completely ruined by the operation. His friends had forsaken him and he now lived an isolated life with his sister. He commented "You know, you really shouldn't do it to us 'gay' people." Hospital records showed that another homosexual, on finding himself with no friends after the operation, committed suicide before the interviews were done.

Few women could be interviewed about sexual activity, but our results do seem to indicate less disturbance than among the men. Of the 12 women who were sexually active before colostomy operations only half remained so afterwards. While three patients gave physical reasons (pain and vaginal stenosis) the rest were unrelated to physical inability. Nine patients who had restorative surgery were sexually active preoperatively; of these a third became inactive after operation—one because of pain, the other two because they found sexual intercourse distasteful.

#### PSYCHOLOGICAL DISTURBANCE

A crude indication of psychological disturbance was attempted in this study by awarding each patient one point for each 10

indices found to be present. The items on the index were as follows: fetishism and ritualism about the colostomy; colostomy rejection; changed body image concept; freakishness; phantom rectum; psychosexual problems; dietary ritualism and fetishism; limitation of social activity; volunteered expressions of depression; treated psychiatric illness since operation; and observer's assessment of psychological disturbance.

Of 120 patients who had undergone surgery for rectal cancer 20 of them fell into the moderately or severely disturbed categories. Of these 20 disturbed patients 19 had a colostomy (Table VIII).

TABLE VIII—Psychological Grading

Score*	Colostomy Operations		Restorative Operations	
	No.	%	No.	%
0 .. ..	15	18	25	68
1-2 .. ..	49	59	11	30
3-4 .. ..	11	13	1	2
≥5 .. ..	8	10	0	0
Total † ..	83	100	37	100

\*Significance of score: 0 = absolutely "normal" persons; 1-2 = mild depressive/anxiety states; 3-4 = more severe psychiatric problems (usually requiring medical supervision); ≥5 = severely disturbed persons.

†One unclassified because of insufficient data.

This method of scoring corresponded closely with professional psychiatric assessment when this was available for comparison. Nevertheless, it does not take account of the length of time after surgery that the interview was conducted. Over five years after operation Grier *et al.*<sup>10</sup> found that three patients out of 50 were still depressed.

More work is needed in this field to establish the incidence of depression and its specificity to colostomy, for a high incidence has been found in general disability.<sup>13</sup> Nevertheless, even our crude methods of assessment have shown convincingly that nearly 25% of all people with colostomies may be depressed. The story of one of the "dead" population may serve to underline the point. An 81-year-old man was depressed after his colostomy operation and was treated by a psychiatrist with antidepressant drugs before he left hospital. Eventually it was decided he could go home to the care of his wife. Two days later he committed suicide, leaving a note to explain that he could not face life with a colostomy.

#### SOCIAL ISOLATION

The scale of social isolation used in this study takes no account of the quality or duration of contact, and refers solely to the activities of the week preceding the interview. A score was compiled for each person according to the methods used by Townsend.<sup>14</sup> Comparison between his randomly selected sample of elderly people and our patients shows a consistently higher degree of social isolation in the colostomy patients (Table IX). This is most pronounced in the group over pensionable age, but

TABLE IX—Social Isolation

Degree of Isolation*	Townsend Study of Old People <sup>14</sup>		Present Study of Colostomy Patients aged:			
			65 Years and Over		Under 65 Years	
	No.	%	No.	%	No.	%
Not isolated ..	156	77	7	17	24	57
Rather isolated ..	27	13	13	32	10	24
Isolated ..	20	10	21	51	8	19
Total ..	203	100	41	100	42	100

\*Not isolated means 36 or more weekly social contacts; rather isolated means 22-35 weekly social contacts; isolated means 21 or fewer weekly social contacts.

the younger group also shows a higher incidence of isolation. In both groups the women were more isolated than the men.

A reason for minor differences in the results may be that children under 15 years old have not been included as social contacts in the present study. An analysis by social class showed that for non-manual classes about half fell into the "not isolated" category, with little difference between the sexes. In social classes IV and V sex became an important factor, with 57% of the men "not isolated" and 21% "isolated," compared with 50% and 23% for the women, respectively. Restriction of social activity is also shown by 10 patients who took annual holidays preoperatively and 12 who had not regularly done so, all stating that they now regarded their colostomy as an insuperable barrier to any future holiday plans.

Thus we may conclude that while a colostomy exerts a definite influence towards the social isolation of the individual, age, sex, and social class are also important variables to be taken into account.

## Health and Welfare Services

### GENERAL PRACTITIONER AND DISTRICT NURSE SERVICES

Clayton Jones<sup>1</sup> pointed out that people with uncontrolled colostomies need special help and advice and that they are of great concern to the general practitioner. Others<sup>15 16</sup> feel that only someone who has a colostomy can understand and help another colostomy patient, and for this reason the Colostomy Welfare Group\* was formed in London. No patients in the present study were members of the group though some had read of it in the press and were interested.

Despite the lack of expertise of the new colostomy patient in managing his stoma and his unhealed perineal wound, only 36% of our patients stated that they had been examined by their general practitioner since discharge from hospital (Table X). Comparison with patients with no colostomy shows little difference between the two groups. Personal visits to the doctors for obtaining repeat prescriptions occur less frequently for patients with a colostomy than for those without (Table XI), largely because the former need continuous supplies of dressings and disposable bags. Nevertheless, this practice may be depriving the colostomy patient of much needed medical support.

TABLE X—Physical Examination by the General Practitioner

	Patients Examined		Patients Not Examined		All	
	No.	%	No.	%	No.	%
Colostomy ..	30	36	53	63	83	100
No colostomy	15	39	23	62	38	100

TABLE XI—Renewal of Prescriptions

Method of Collection	Colostomy		No Colostomy		All	
	No.	%	No.	%	No.	%
Personal visit	28	39	19	50	47	39
Message + collection ..	53	64	15	39	68	56
Not applicable	2	2	4	11	6	5
Total ..	83	100	38	100	121	100

The district nurse visited only 47% of the colostomy patients (and 16% of those who had restorative surgery). The time of attendance ranged from one visit to regular visits over 52 weeks (Table XII), with an average time of attendance in London being 7.2 weeks and in Southend 12.4 weeks. This difference is

probably explained by the fact that more London patients were discharged from hospital to a convalescent home, while in Southend they went straight home. District nurses were rarely criticized, but when they were it was because of too few visits. Nine patients were visited for less than two weeks, some only once or twice.

TABLE XII—District Nurse Visits

No. of Weeks Visited	Colostomy		No Colostomy	
	No.	%	No.	%
0-4 .. .. .	24	62	2	33
5-12 .. .. .	6	15	2	33
13-24 .. .. .	5	13	1	17
≥25 .. .. .	4	10	1	17
Total ..	39	100	6	100

Thus 34 (41%) colostomy patients neither saw their general practitioners regularly nor had contact with a district nurse. Seventeen of this undersupervised group had more than five colostomy actions daily, and for only four of them was inadequate domiciliary supervision compensated by more frequent hospital outpatient visits (Table XIII). There was no correlation between the length of time since operation and the frequency of outpatient appointments for this group.

TABLE XIII—Patients with Hyperactive Colostomies and Inadequate Domiciliary Supervision

Hospital Outpatient Appointment Over Last Year	Patients Needing Supervision	
	No.	%
Every 1-2 months .. .. .	4	23.5
Every 3-5 months .. .. .	4	23.5
Every 6-12 months .. .. .	8	47.0
None .. .. .	1	6.0
Total ..	17	100.0

### USE OF COMMUNITY SERVICES

Muriel Skeet<sup>17</sup> found that nearly half of the patients recently discharged from hospital were getting sufficient care from friends and relatives. For the rest the number of services organized by the hospital were doubled by the general practitioner within two weeks of discharge. Even so, 45% of patients were receiving inadequate care. Disposal of soiled dressings was also found to be a problem, with nearly a quarter of the patients putting soiled dressings in dustbins.

In our study 21 patients (17%) were in receipt of community care services (Table XIV), and 12 of these had a colostomy. Contrary to the findings of Skeet many patients expressed dissatisfaction with the advertisement and provision of services. The home help service came in for most criticism. There were complaints that lack of modern cleaning aids meant that laundry and floors were neglected. Others spoke of home helps who never came or who arrived only after the crisis of the first few weeks home from hospital were over. These findings accord with a recent study,<sup>22</sup> which said "With regard to hospital discharge cases . . . the existing provision needs to be more than doubled."

As about half of the patients were of pensionable age it is surprising that only three used Meals on Wheels. In common with another recent study<sup>18</sup> we found that hardship was experienced at weekends when the service did not operate. The laundry service for incontinent patients was used by only one man. Very few knew of its existence, but many commented on how useful it would have been at first, especially during the winter. No one in this study was using a soiled dressing collection service. Paper dressings and polyethylene, carefully cut up, were flushed down the lavatory by 38 patients. A further 26

\*Colostomy Welfare Group, St. Luke's Hospital, Sydney Street, London S.W.3.

TABLE XIV—Community Services Used

Service	No. of Patients	
	Colostomy	No Colostomy
Home helps . . . . .	7	5
Social worker . . . . .	3	4
Hire/loan equipment . . . . .	4	0
Meals on Wheels . . . . .	3	0
Local Authority laundry service . . . . .	0	1*
Welfare officer for the blind . . . . .	1	0
Local Authority library delivery . . . . .	0	1
Health visitor . . . . .	0	1
Chapel social worker . . . . .	0	1
Total . . . . .	18†	13†

\*This patient had an ileostomy.

†Some patients used more than one service. Total of 21 patients involved altogether.

patients were lucky enough to have facilities for incineration. The remaining 19 disposed of their soiled dressings in the dustbin. This last method of disposal often involved bizarre practices to prevent neighbours finding out about the contents of the packages in the dustbin.

Community services were arranged by the hospital for 12 of the 21 patients. The general practitioner or district nurse arranged them for six others, and the rest obtained them mainly on their own initiative.

### Conclusion

It seems true to say that many of the colostomy patients we visited "led useful lives, kept in good health and seemed little handicapped by the colostomy."<sup>23</sup> Nevertheless, in each area of daily activity and physical or mental well-being we studied about a quarter of the colostomy patients were found to be in need of help or advice. This compared with a very low proportion of those who had had restorative surgery.

Convalescent homes were often found to be inadequately reinforcing the hospital teaching about colostomy management and use of drugs and appliances. Some homes, however, were highly praised—one in particular, which specialized in men with intestinal stomata, allowed a high degree of autonomy, but managed at the same time to have expert help and advice always available.

That the standard of housing enjoyed by our patients corresponded so closely with the general standard for London and Essex<sup>5</sup> illustrates that local housing authorities have little appreciation of the plight of colostomy patients living in substandard housing. Eighteen patients who lacked some of the basic amenities for hygiene were still waiting to be rehoused, some since their operations more than three years previously.

Most patients were uncritical of the treatment they had received from the health and social services. A few wondered why they had been treated at home for minor anorectal lesions for so long before being sent to the hospital. Twenty-nine (36%) felt that the general practitioner lacked the knowledge and expertise to care for them after surgery and said that they would return to the hospital for colostomy advice. Several general practitioners have pointed out that in the average practice there may be only one or two colostomy patients, so that the demand for this sort of expertise from the individual general practitioner is small. Nevertheless, hospital clinics did not seem to give much better follow-up care. It seems, therefore, that there is a more basic problem.

### DIFFICULTIES OF COMMUNICATION

Arie has pointed to the difficulties of communication between doctors and patients.<sup>19</sup> He found that 80% of doctors come from social classes I and II, whereas 80% of their patients come from social classes III, IV, V. An illiterate patient in the present study had missed several hospital clinics because he could not read his appointment card. When he finally arrived at a clinic his reply to the doctor's inquiries was, "I'm fine thank you";

he made no mention of his diarrhoea or his need for welfare services.

Social class is not the only barrier. Another patient did not return to her doctor to renew a prescription which she had found beneficial mainly because she did not want to trouble him. A recent study showed that 17% of the sample failed to obtain treatment for pain or discomfort.<sup>24</sup> Reasons given for this failure suggested that people felt an obligation to "manage" and not to trouble the doctor.

Recognition of the communication problem has resulted in the creation of several centres in America designed to provide continuity of help and advice for the colostomy patient.<sup>20</sup> From the time of initial diagnosis the patient is in contact with the centre, where medical and nursing expertise together with the experience of other patients is available at any time. In Britain greater co-ordination of domiciliary care resulting from the implementation of the recommendations of the Seeborn report should help to diminish the problem. The slow growth of group practices with nurse and health visitor attachments in London may account for so many patients in this study living in unnecessary difficulty.

Three major conclusions emerge from this study. The first is the immense price paid by the patient for his cure from cancer—a price paid in physical discomfort and in psychological and social trauma. Secondly, not only are persons thus damaged not identified but we have been unable to find any common factor which could identify them before surgery. Thirdly, the existence of psychological disturbance is rarely diagnosed. There are several reasons for this: a lack of contact between the general practitioner and the hospital and environmental services; within the hospital by the transitory nature of the junior staff who often see patients for follow-up, and the demands made on their time. Society has determined that life must be saved at all costs, and the skill of the surgeon is directed towards this end. We have shown that it is now time to look more closely at the costs and at those who bear them. Far more emphasis must now be placed on the quality of the life saved.

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