

Stigma in patients with rectal cancer: a community study

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SUMMARY A self-rating measure of stigma and several supplementary questions were devised in order to assess perceived stigma in a community survey of the quality of life in 420 rectal cancer patients, of whom 265 had a permanent colostomy. Half the patients felt stigmatised, higher proportions being observed among younger patients and among those with a colostomy. Feelings of stigma were associated with poor health, particularly emotional disorders, with the presence of other medical problems, and with disablement. Patients who perceived stigma made more use of medical services but were less satisfied with them, particularly with regard to communication with health professionals. Socio-economic factors, such as employment status, higher income, and higher social and housing class, did not protect patients against feeling stigmatised by cancer or by colostomy. Most patients, with or without stigma, enjoyed close relationships with intimates, but the stigmatised were more likely to have withdrawn from participation in social activities. Assessing stigma by self-rating gives information which adds to that obtained by the usual methods of assessing quality of life.

Treatment for rectal cancer involves the majority of patients in radical mutilating surgery, the burden of a colostomy, and low expectation of survival.^{1–4} Although new techniques to reduce the number of rectum sacrificing operations are constantly being sought, about two thirds of rectal cancer patients face the double stigma of cancer and colostomy.^{5–7}

Serious complications of colostomy, such as herniation, retraction, stenosis, and prolapse, are not uncommon.^{8,9} It is estimated that up to half of colostomy patients have urinary complaints, and sexual functioning in men is often disturbed or eliminated after abdominoperineal resection.^{10–16} It is also reported that up to one third of women with stomas experience a reduction in sensation or, conversely, pain during intercourse.^{14,17,18}

About half of colostomies never discharge regularly;^{19,20} continence of faeces and flatus cannot be achieved as there is no sphincter under voluntary control.²¹ The most common method of managing a colostomy in Britain is to collect the stools in a bag attached to the body by adhesives or belts.²² Disposal of used bags in public lavatories or at work is often a problem for men, although women can use containers provided for sanitary towels.²³ Although many technical difficulties appear to have been resolved with the development of odour and flatus

proof bags, there are still problems with odour, noise, and leakage.²⁴ Moreover, the practicalities of managing a stoma physically violate strong social taboos about defaecation.

Briggs and colleagues have drawn upon the classic model of stigma management to describe how colostomy patients may cope with their deviance.^{25,26} Some may withdraw from normal social relationships, because they are overwhelmed by stigma, and live as recluses or as permanent invalids. Others may try to conceal their abnormality to 'pass as normal'. But passing is not completely satisfactory because stoma is always in danger of becoming manifest by noise, odour, or accident. A third alternative is to 'come out' by objectifying the abnormality and accepting the colostomy merely as an eccentricity and not as the central focus of one's life.

Intensive studies of stoma patients suggest that they must work through profound intrapsychic problems associated with reactions to loss of a body member.²⁷ This is similar to the grief and mourning associated with loss of a family member.²⁸ There is also a social dimension to this process; people who have lost a spouse are in a stigmatised social position, that of the widowed.²⁹ Rectal cancer patients with an anastomosis are also in an ambiguous social position,

that of the chronic patient with the invisible stigma of cancer.³⁰ Rectal cancer patients with a colostomy have multiple burdens: the stigma of cancer, the stigma of physical deviance, and the intrapsychic problem of incorporating a new body image into their concept of themselves. Their social position is that of the chronic patient with a permanent stigma which, although hidden, is always in danger of becoming manifest.^{31–33}

Until the present survey there had been no empirical studies of stigma among patients with rectal cancer with or without colostomy. We describe an effort to ascertain the presence and degree of stigma in a large number of such patients, to examine the association between stigma and other factors, and to investigate the value of considering stigma as a psychosocial dimension in its own right to complement the traditional approach to quality of life in terms of physical, emotional, and social well-being.

Methods and patients

We have used selected results from a population-based study of rectal cancer patients living in five health districts in south-west and south-east London. Fuller details of the methods used are given elsewhere.³⁴ Appropriate permission was sought and obtained to use the records of the South Thames Cancer Registry to identify all patients, not known to be dead, who had been diagnosed as having rectal cancer and had been treated by radical surgery between 1958 and 1978, with an address in one of the selected health districts. Consent to write to the patient to request an interview was obtained for 518 cases. Of these, 25 died before they could be interviewed, 24 were terminally ill, 21 had moved outside the study area, 7 could not be traced, and 21 did not wish to be interviewed. Four hundred and twenty patients were interviewed at home by one of 28 health visitors trained in the administration of a semistructured questionnaire (available from authors). The word 'cancer' was not used in the patient questionnaire; and 'bowel condition' was the agreed circumlocution. Interview data were augmented by questionnaires completed by the patients' general practitioners and by the interviewers.

The study was designed to yield information on the following groups of topics: quality of life; physical, emotional, and social health—as perceived by the patient and assessed by both the general practitioner and the health visitor, supplemented by the Leeds scales for the self-assessment of anxiety and depression.³⁵ Stigma was included in the definition of quality of life. Clinical variables comprised details of

symptoms, chronic illness, and medication. Disability was assessed using an instrument developed by Garrad and Bennett.³⁶ The buffer variables, which might protect patients against poor quality of life, included use of medical and community services, satisfaction with services, and personal, family, and socioeconomic circumstances.

Stigma is the result of interaction between individual and community values. This study identified damaging social influences as perceived by the patient. Other people were not asked about their attitudes and behaviour towards rectal cancer patients and colostomy; questions concentrated on the subjective assessment of stigma.

A stigma self-rating measure was devised, consisting of statements about avoidance of others, avoidance by others, feelings of self-consciousness, of unattractiveness, and of being different from other people. Items were scored from 0 (complete disagreement) to 3 (complete agreement) with each statement. In the absence of independent judgements about patients' feelings of stigma, we could not determine a cut-off point based on total scores. The arbitrary solution was to use the extremes: 0 or 1 (negligible stigma) on every item against the rest, ie, 2 or 3 (some stigma) on any item. Responses were also tabulated by dividing scores above and below the median. Severe stigma was defined as the upper 15% of the frequency distribution of the scores. The scale was supported by additional questions about perceptions of changes since surgery—in self-esteem, in physical appearance when fully dressed, and in married life. Responses were cross classified by age, sex, presence or absence of a colostomy, and years since surgery, and tested for statistical significance using the chi-squared test.

The 600 variables on which the study is based were collapsed into nine summary variables by principal component analysis. For each topic investigated, all indicator variables related to that topic were used as data for the principal component. These summary variables were used to calculate the correlations and regressions described. All associations mentioned in the text are statistically significant unless stated otherwise.

Results

A total of 420 interviews were successfully completed, half with men and half with women; 265 (63%) had a permanent colostomy. The others had been left with a functioning rectum after resection of the cancer and anastomosis (referred to subsequently as 'anastomosed patients'). The demographic and socioeconomic characteristics of the population studied and their years since surgery are shown in table 1.

Table 1 Social and economic characteristics, presence of colostomy, and number of years since surgery

	Age (years)						Total (n = 420) %
	<65		65-74		75+		
	M (n = 64) %	F (n = 52) %	M (n = 80) %	F (n = 80) %	M (n = 66) %	F (n = 78) %	
Marital status							
Single	2	7	4	5	2	14	6
Married/cohabiting	81	67	82	46	73	18	60
Widowed	5	15	11	41	26	68	29
Separated/divorced	8	10	1	8	0	0	4
Homosexual	5	0	1	0	0	0	1
Living alone	8	19	10	39	23	56	27
Left school, age 14 or less	63	52	69	66	73	71	66
Employed							
Part-time	6	21	14	6	5	0	8
Full-time	70	17	5	1	2	0	14
Gross weekly household income*							
<£60	10	36	52	71	75	91	58
>£100	56	40	20	13	10	4	22
Social class							
Manual	51	49	52	48	65	59	54
Non-manual	49	51	48	52	35	41	46
Housing class							
Owner occupier	66	56	58	53	55	46	55
Private tenant	13	21	19	16	17	23	18
Council tenant	22	23	24	31	29	31	27
Colostomy present	69	65	70	55	59	62	63
Years since surgery							
1-5	59	65	58	46	44	47	53
6-10	22	23	24	30	27	18	24
11+	19	12	18	24	29	35	23

*1980 prices

STIGMA SELF-RATING

Responses to the separate items in the stigma self-rating are shown in table 2. Taking the 'sometimes' or 'definitely' ratings together, the most frequent item was 'self-consciousness' (31%) followed by 'decreased attractiveness' (27%), 'avoidance of other people' (14%), 'feeling different from others' (11%), and 'avoidance by others' (4%). Patients with or without colostomies differed significantly on 'self-consciousness' and 'feeling different'. Individual items were significantly intercorrelated ($p < 0.001$), the highest coefficients of correlation occurring between 'self-consciousness' and 'feeling different' (0.45), and the lowest between 'self-consciousness' and 'avoidance by others' (0.18).

On the basis of the self-rating, half the patients were classified as feeling some degree of stigmatisation (table 3). Among men, this perception declined with advancing age, but among women few differences were observed among different age groups. Feelings of stigma were significantly more common among colostomy patients but were not related to years since surgery. Overall 16% of patients felt severely stigmatised, the proportion being higher in younger than in older patients, and

particularly noticeable among younger women and colostomy patients. There were no differences in the severity of stigma perceived by years since surgery.

Overall 37% of patients said that they felt worse about themselves than before their bowel surgery. Regardless of age, sex, or years since surgery, a colostomy was significantly associated with this aspect of stigma.

Patients with lowered self-esteem were asked to explain how their feelings about themselves had changed. Among both colostomy and anastomosed patients, 56% said they felt anxious, depressed, vulnerable, lonely, weak or oversensitive as a result of bowel surgery; 38% with colostomies felt dirty, embarrassed, ashamed or self-conscious about the stoma, especially in public or in company; and 23% never stopped thinking about their colostomy and bowel action, and their preoccupations reminded them constantly of their abnormality.

Sixteen percent of patients felt that their appearance when fully dressed had changed since surgery so that other people noticed it, and this was more frequent among women and among colostomy patients (table 3). There were no significant variations by age or years since surgery. Patients who

Table 2 Items in stigma self-rating by colostomy and anastomosis

	Colostomy (n = 265) %	Anastomosis (n = 155) %	Total (n = 420) %
I avoid other people these days			
Not at all	76	74	75
Not much	11	11	11
Sometimes	8	12	10
Definitely	4	3	4
No reply	1	0	0.5
I feel that other people are avoiding me these days			
Not at all	87	90	88
Not much	7	7	7
Sometimes	3	2	3
Definitely	2	0	1
No reply	1	1	1
I feel less attractive than I used to			
Not at all	53	51	52
Not much	21	18	20
Sometimes	17	20	19
Definitely	8	10	8
No reply	1	1	1
I feel odd and different from other people			
Not at all	68	82	75
Not much	17	12	14
Sometimes	9	4	7
Definitely	5	1	3
No reply	1	1	1
I feel self-conscious and embarrassed			
Not at all	43	59	51
Not much	16	23	20
Sometimes	31	16	23
Definitely	9	1	5
No reply	1	1	1

Colostomy v 'avoids others', 'others avoid', 'less attractive' NS.
 Colostomy v 'feels different' p<0.01.
 Colostomy v 'self-conscious' p<0.001.

Eighty three percent with colostomies were sure the stoma showed because it made a bulge noticeable through their clothing; or they thought the bag rustled when they moved, or filled with air from flatus; or they felt sure that others noticed the loose shapeless clothing they wore to try to conceal the stoma. A further 6% had lost interest in their appearance since surgery because they always felt unclean and that others noticed this change. One man claimed that he had lost all his teeth because of eating strong mints in an effort to hide the smell of the colostomy.

Married patients and those widowed subsequent to surgery were asked if their married life had changed as a result of the bowel condition (table 3). The stigma of a deteriorating marriage was predominantly felt by men, by younger patients, and by those with a colostomy, but one fifth of the older men also suffered this problem. There were no significant differences by years since surgery. This indicator of stigma was twice as frequent among colostomy patients. Patients who said that their married life had suffered since surgery, when asked to explain why, generally mentioned the shame and embarrassment caused by the colostomy. Fifty three percent mentioned feelings of revulsion aroused by the stoma; the same proportion had had no sex since surgery; either because they were impotent or because their libido had suffered, presumably as a result of the bowel condition. Two patients said that the need to be nursed by their partner had worsened the relationship. Five said that they had never got on with their partner and that the bowel condition had driven them further apart.

felt stigmatised by a noticeably changed appearance were asked to describe how it had changed. A quarter of both colostomy and anastomosed patients said that they always looked weak, tired, and depressed.

STIGMA AND ITS CORRELATES

Table 4 shows the relation between stigma and the summary variables obtained by principal component

Table 3 Stigma self-rating and supplementary questions by age, sex, colostomy, and anastomosis

	Age (years)						Colostomy (n = 265) %	Anastomosis (n = 155) %	Total (n = 420) %
	<65		65-74		75+				
	M (n = 64) %	F (n = 52) %	M (n = 80) %	F (n = 80) %	M (n = 66) %	F (n = 78) %			
Stigma self-rating									
Some stigma	57	53	46	51	31	58	54	41	49
Severe stigma	22	30	12	12	6	17	26	13	16
Feelings about self worse	40	39	24	33	40	43	43	27	37
Appearance worse when fully dressed	11	21	10	19	11	23	20	9	16
Married life worse*	48	27	27	27	19	9	29	14	23

*Single people and those divorced or widowed before surgery were not asked this question, n = 389.
 Age v some stigma p<0.01; v severe stigma p<0.05; v feelings about self, appearance NS; v married life p<0.001.
 Sex v some stigma, appearance p<0.01; v severe stigma p<0.05; v married life p<0.001; v feelings about self NS.
 Colostomy v some stigma, appearance p<0.01; v severe stigma p<0.05; v feelings about self, married life p<0.001.

analysis for colostomy patients and anastomosed patients separately. The relation between stigma and important items comprising the summary variables are described in the text. The highest correlations occurred between stigma and poor emotional health for both groups of patients. Those who felt stigmatised were much more likely to perceive their emotional health as poor (39% v 12%) and to score as depressed (38% v 12%) and anxious (42% v 10%) on the Leeds scales. They were more likely to be assessed as emotionally disturbed by the health visitor interviewer (37% v 16%) and to have had a 'nervous breakdown' since surgery (12% v 3%).

Table 4 Correlation coefficients: stigma with other summary variables by colostomy and anastomosis

	Colostomy (n = 265)	Anastomosis (n = 155)	Total (n = 420)
<i>Quality of life variables</i>			
Poor physical health	0.40‡	0.42‡	0.40‡
Poor emotional health	0.65‡	0.73‡	0.67‡
Poor social health	0.28‡	0.20†	0.25‡
<i>Clinical variables</i>			
More specific medical problems	0.36‡	0.29‡	0.34‡
More disablement	0.25‡	0.12**	0.22‡
<i>Buffer variables</i>			
More service use	0.04**	0.24†	0.10*
Less satisfaction with services	0.22‡	0.18†	0.21‡
Less personal/social resources	0.08**	0.01**	0.06**

*p<0.05.

†p<0.01.

‡p<0.001.

**NS.

Stigma and poor physical health were also correlated. Perception of poor physical health was more closely associated with feelings of stigma in anastomosed than colostomy patients (47% v 37%), but in both groups the proportion of unstigmatised patients perceiving poor physical health was substantially lower (17%). The stigmatised were more likely to be assessed as having poor physical health by the health visitor (39% v 18%). The general practitioner's assessment of his patient's physical and emotional health was not associated with stigma.

Stigma and poor social health were more highly correlated in patients with a colostomy than in those with an anastomosis. The overall correlation was lower than between stigma and the other quality of survival variables because stigma was not associated with levels of social interaction between patients and friends and relatives. Indeed, nearly all patients continued to enjoy close and supportive relationships with intimates (85%). Stigma, particularly among colostomy patients, was associated with restriction of other social activities. The stigmatised were more

likely to leave the house less frequently than once a week (24% v 10%), to be less interested in customary social activities (53% v 30%), and to participate in them less (73% v 51%). In the anastomosed group, the same tendencies were observed, but the differences did not reach statistical significance.

Stigma was correlated with the presence of specific medical problems. In both groups of patients, the stigmatised were more likely to sleep poorly (34% v 23%), to have a poor appetite (27% v 11%), and to have low energy (47% v 33%). Stigma among colostomy patients was associated with pain (44% v 28%), sexual incapacity (67% v 55%), other complications of surgery (58% v 46%), the use of analgesics (45% v 27%), and the use of tranquilisers (14% v 4%). Stigma was not associated with the presence of other chronic ailments or with the use of hypnotics.

Feelings of stigma were significantly correlated with the inability to carry out routine domestic tasks among colostomy patients (27% v 15%), but not with the presence of a disability *per se* among either colostomy or anastomosed patients.

The correlation between stigma and frequent use of services was higher in anastomosed than in colostomy patients. Among the latter, the stigmatised were more likely to have had recent contact with the general practitioner (32% v 19%), and to have been a psychiatric inpatient (8% v 2%). Among the former, patients with stigma were more likely to have consulted a psychiatrist (11% v 2%). Stigma was not associated with the use of hospital inpatient and outpatient services, nor with the use of community social welfare services.

Stigma was inversely correlated with service satisfaction. Stigmatised patients were more likely to feel that the general practitioner did not discuss things fully (39% v 23%) and to feel dissatisfied with seldom being attended by the same doctor at hospital follow ups (38% v 19%). Other indicators of service satisfaction, for example, sufficient communication with hospital doctors, sufficient information about the operation and the bowel condition, being alerted to complications of surgery, and other problems with the services, were not associated with stigma.

Stigma was not correlated with any of the personal and social characteristics investigated, either for the total study population or for colostomy and anastomosed patients considered separately.

STIGMA AND THE OTHER QUALITY OF LIFE VARIABLES

The independent effects of emotional, physical, and social health on stigma were examined by using multiple regression (table 5). For each variable, its effects were examined (1) after controlling for all

other variables (other quality of life variables, and clinical and buffer variables), and (2) after controlling for all but the other quality of life variables. The results suggest that the four quality of life variables are, to some extent, aspects of the same phenomenon. They are not simply tautologous, but they are partly interdependent. The strongest relation is observed between perceived stigma and poor emotional health. The proportion of variance in stigma explained by simple correlation with poor emotional health is 45%, reduced to 27% after controlling for the confounding effect of the clinical and buffer variables, and to 21% after controlling for the effects of the other quality of life variables. The proportion of variance in stigma explained by the other quality of life variables is less, but all the variables in the study acting together explain half the total variance in stigma.

Discussion

Our results showed that stigma, or the assortment of variables grouped under the rubric ‘stigma’, was a definite part of the experience of many of the patients studied. Younger patients, particularly men, felt more stigmatised than older patients, according to the stigma self-rating and the indicator of quality of married life. Women of all ages were more likely to feel the stigma of a noticeably changed appearance. The indicator of lowered self-esteem did not vary with age and sex but showed, like all the stigma indicators, that colostomy patients felt more stigmatised than anastomosed patients.

Feelings of stigma varied with the other quality of life variables—physical, emotional, and social health—with the clinical variables, and with the buffer variables of service use and satisfaction. But having a job, a higher income, a higher social and housing class, and other social and economic factors did not appear to protect any category of rectal cancer patient against feelings of stigma. The better

off were, of course, immune from the service-induced stigma attached to poverty, unemployment, council housing, the negotiations required to receive cash benefits, and the like, but evidently the personal stigma of cancer and/or a mutilated body was powerful enough to overcome the protection of a privileged social position.³⁷

In terms of the model of stigma management described in the introduction, our results suggest that the majority of patients had not allowed stigma to overwhelm them. A large proportion of those who had a colostomy did try to control information about the stoma by not showing it to spouse (33%), family (90%), or friends (90%). Moreover, less than half reported that the stoma had been seen by a health professional. There was no significant difference in this regard between stigmatised and stigma-free patients with a colostomy. This may mean that the stigmatised were trying to conceal the source of the stigma by denial, and that the stigma-free were protecting themselves from stigmatisation by the same mechanism.

Evidence from this study suggests that the perception of stigma was closely but selectively associated with behaviour. In personal relationships, both the stigmatised and the stigma-free maintained close and frequent contact with family members and friends. Patients seemed to be able to overcome or set aside feelings of stigma in certain formal situations: the same proportion of the stigmatised and the unstigmatised were working (50%). However, in the realm of recreational activities outside the home, and interest and participation in informal community life, the stigmatised were much more likely to have cut themselves off. This sort of isolation may represent secondary deviance.³⁸ In this regard, it has been observed that some colostomy patients attempt to keep stigma from engulfing them by distancing the stoma by calling it a nickname.¹⁸ Less than one fifth (18%) of colostomy patients in this study used a nickname, for example, Fred or Mount Aetna.

Table 5 Multiple regressions of other quality of life variables on stigma

Dependent variable	Independent variable	Controlling for	% Variance explained	p
Stigma	Poor emotional health	Uncontrolled	45	<0.001
		All other variables	21	<0.001
		All but other quality of life variables	27	<0.001
Stigma	Poor physical health	Uncontrolled	32	<0.001
		All other variables	0.3	<0.05
		All but other quality of life variables	5	<0.001
Stigma	Poor social health	Uncontrolled	6	<0.001
		All other variables	0.7	<0.001
		All but other quality of life variables	3	<0.001
Stigma	All variables		50	

Our results confirm that cancer is, in itself, a stigmatising condition: and a colostomy exaggerates this. Moreover, perceptions of stigma do not decline with years since surgery, suggesting that special efforts are needed, perhaps in the preoperative period, and certainly early in the postoperative period, to help patients facing mutilating or disfiguring surgery and those suffering from cancer to resist the additional burden of stigma and its social and psychological effects.

Our experience suggests that efforts to develop a self-rated stigma measure should continue and might lead to an important expansion of the methods currently used to measure quality of life, not only in health care studies but in clinical practice.

We thank the South Thames Cancer Registry, the Department of Surgery at St George's Hospital, the consultant surgeons and general practitioners of the patients studied, the health visitors who conducted the interviews, and the patients who participated as respondents. Mrs S Finer was responsible for data processing. The study was funded by the Department of Health and Social Security.

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