

# Patients' Views of a Colostomy for Fecal Incontinence

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**INTRODUCTION:** Formation of a permanent stoma often is seen as a last resort when all other interventions for fecal incontinence have failed. However, no previous study has examined patients' views of a colostomy to manage fecal incontinence. **METHODS:** People who had a colostomy to manage fecal incontinence were recruited via an advertisement in the magazine of the British Colostomy Association or from those operated at a specialist colorectal hospital. Four questionnaires were sent, asking about the stoma, previous incontinence, anxiety and depression, and quality of life. **RESULTS:** A total of 69 replies were received. Respondents were 11 males and 58 females with a median age of 64 years and a median of 59 months since the operation. Rating their ability to live with their stoma now on a scale of 0 to 10, the median response was 8 (range, 0-10). The majority (83 percent) felt that the stoma restricted their life "a little" or "not at all" (a significant improvement from perceived restriction from former incontinence,  $P = 0.008$ ). Satisfaction with the stoma was a median of 9 on a scale of 0 to 10 (range, 0-10). Eighty-four percent would "probably" or "definitely" choose to have the stoma again. Quality of life (SF-36) was poor, but neither depression nor anxiety was a prominent feature. **CONCLUSIONS:** The majority of previously incontinent people were positive about the stoma and the difference it had made to their life. However, a few had not adapted and disliked the stoma intensely. Health care professionals should discuss a stoma as an option with patients whose lives are restricted by fecal incontinence. [Key words: Fecal incontinence; Colostomy; Stoma; Quality of life]

Fecal incontinence affects more than 1 percent of community-dwelling adults.<sup>1</sup> Considerable advances have been made in the diagnosis and treatment of fecal incontinence.<sup>2</sup> However, many patients have persistent symptoms and major negative impact on quality of life. Formation of a permanent stoma is a radical option to contain fecal incontinence in a socially hygienic manner. It has not been widely discussed in the literature, but often is seen as a last resort in clinical practice.<sup>2</sup> No previous study has examined patients' views of a colostomy formed to manage fecal incontinence.

## PATIENTS AND METHODS

People with previous formation of a colostomy to manage fecal incontinence were recruited via an advertisement in the magazine of the British Colostomy Association (BCA) or from the authors' own hospital (patients identified from a research records database of all admissions during the previous 10 years and case notes reviewed to check that fecal incontinence was the sole indication for stoma formation). Patients who had formation of a stoma for cancer, bowel disease, or incontinence secondary to another bowel disease were excluded, as were patients with an ileostomy.

Participants were sent four questionnaires:

1. A specific questionnaire developed for this study asking about demographic details, the stoma operation, problems with the stoma, previous incontinence history, and feelings about the stoma and its influence on everyday life;

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2. The SF36<sup>3</sup>
3. The Hospital Anxiety and Depression Scale<sup>4</sup>;
4. A condition-specific quality of life questionnaire developed for a previous study of fecal incontinence.<sup>5</sup>

## RESULTS

Fifty-four people responded to the advertisement in the BCA magazine and were sent the questionnaires, of whom 49 returned completed questionnaires (91 percent response; 1 person had died and 4 did not reply). Forty-two patients were identified from the hospital database. Four of these also had replied to the BCA advertisement, therefore, 38 new people were identified and sent questionnaires. Of these 38, 20 completed replies (53 percent response; an additional 3 had died and 1 was returned as gone away). There were a total of 69 completed responses.

Patients recruited *via* the BCA might be different from those recruited *via* the hospital so throughout the analysis the response from the two groups was compared. The only significant difference detected was that patients recruited *via* the hospital had a median of 95 months since surgery—BCA members 47 months ( $P = 0.005$ ). Because no other differences were detected in age, gender, coexisting disability, or replies to questions, results were combined for presentation.

Respondents had a median age of 64 (range, 34–88) years at the time of response. Median age at the time of stoma formation was 59 (range, 31–79) years. There were 11 males and 58 females. Thirty-nine classed themselves as having a major illness or disability, apart from the stoma (13 specified respiratory diseases, 14 musculoskeletal disability, 1 stroke, 1 multiple sclerosis).

### Hospital Experience

Patients recalled a median of 12 (range, 5–77) days in hospital at the time of stoma formation (5 could not remember or did not reply). Twenty-one felt that they had experienced complications at the time of surgery, including one cardiac arrest, one subsequent bowel resection, and resultant short-bowel syndrome, one who underwent three failed laparoscopic attempts to form a stoma and then open surgery, and six others who were reoperated for resiting of the stoma within the perioperative period, one who was reoperated because the wrong end of bowel was pulled through, and another because stool was passed from the rec-

**Table 1.**  
Problems With the Stoma

	Since the Operation	Currently
Mucus leakage	50 (9 operated)	41
Need to wear a pad	38	29
Sore skin or rashes around stoma	40	29
Bags do not stick well	16	16
Leakage from bag	30	27
Ballooning of the bag	34	1
Prolapsed stoma or hernia	29 (42%)	37
Retracted or narrowed stoma	1	6
Pancaking	5	5
Other	13	11

tum; six mentioned infections, including three abscesses, and one ruptured spleen.

When asked to evaluate their experience in the hospital, 42 chose "about as I expected," 13 "not as bad as I expected," and 13 "much worse than I expected" (1 did not reply).

### Current Stoma Experience

Sixty-three patients used stoma pouches alone; three used a pouch plus stoma irrigation (1 also with a plug), two used irrigation with no pouch (1 did not reply). Respondents had experienced a variety of problems with the stoma, currently or since the operation (Table 1). Only ten patients reported no current problems with their stoma. "Other problems" included bleeding and abdominal pains.

A specific question was asked about mucus leakage. Forty-one currently experienced anal mucus leakage (29 wore a pad for this) and another nine had previously undergone a proctectomy for this problem (1 person did not reply). In total, 50 of 68 respondents (74 percent) had experience of mucus leakage, with 56 percent of the sample needing a pad or surgery for this symptom.

Thirty-four of 69 people stated that they had required further surgery since the original stoma formation. Some of these were minor, such as disimpaction or removal of a mucus plug under anesthetic. More major surgery included 15 revisions or re-sitings of the stoma, 19 hernia repairs in 14 people, 4 of whom were awaiting further hernia repair, and 9 proctectomy for mucus leak. One person had undergone two operations for rectal prolapse, one an abdominoperi-



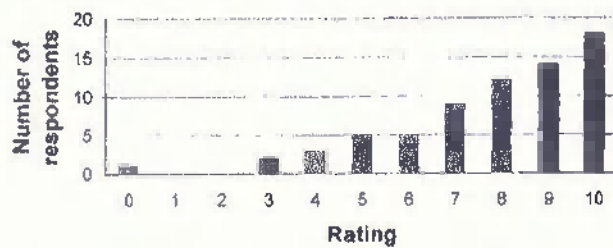


Figure 1. Please rate how good is your ability to live with your stoma now.

neal excision of the rectum for fistula, one removal of a tumor from the rectal stump, three division of adhesions, one major bowel resection after perforation during bowel irrigation, and one small-bowel ischemia. Both of the latter two resulted in short-bowel syndrome, necessitating permanent parenteral nutrition.

Respondents were asked to rate their ability to live with their stoma now on a scale of 0 to 10. The median response was 8 (range, 0–10; Fig. 1). Patients reporting no current problems with their stoma had a median rating of 9.5 for their ability to live with their stoma now, those reporting at least one current problem rated this a median of 8 ( $P = 0.01$ ). There was no difference in rating of ability to live with the stoma now between those who reported a current major disease or disability and those who did not.

The majority (83 percent) felt that the stoma, within the past month, restricted their life a little or not at all (Fig. 2). Of those who specified restrictions, these included being very conscious of the location of toilets, travel restrictions, and feeling self-conscious about noise or smells and the possibility of bag or anal leakage.

### Previous Incontinence History

Respondents reported a median of eight (range, 0.5–45) years of fecal incontinence before stoma formation (6 did not reply or could not remember). When asked when the incontinence started, 18 replied after an operation (6 hemorrhoidectomy, 3 anal fissure, 2 spinal surgery, and 1 each of cholecystectomy, hysterectomy, anterior rectal resection, lateral sphincterotomy, urostomy, colposuspension, rectal prolapse). Fourteen felt that the incontinence had started after having a baby, 21 did not know or felt that there was no apparent reason for onset, 1 did not reply, and 15 cited other reasons (including spinal cord injury, multiple sclerosis, diabetic autonomic

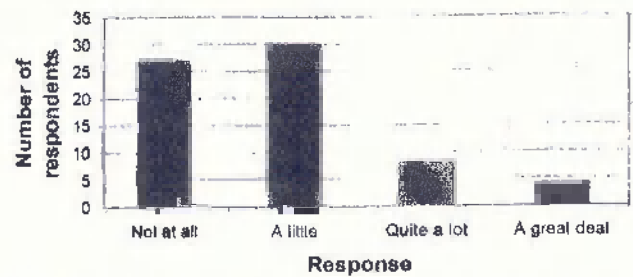


Figure 2. Do you feel that your stoma currently restricts your life?

neuropathy, rectal prolapse, severe constipation, stroke, radiotherapy, stress, and a gut infection).

A variety of different treatments had been tried. Fifty-two of 69 patients (75 percent) reported previous surgery for incontinence (with a median 2 (range, 1–17) operations in these 52 people). Of these, 34 reported previous anal sphincter repair, 17 previous postanal repair, 15 surgery for rectal prolapse, and 6 other operations. Nineteen recalled trying exercises or biofeedback and five other treatments, including three perianal Bioplastique injections.

Respondents were asked for their recall of previous bowel symptoms. Fifty-eight reported urgency, with fewer than one minute (38 people) or one to five minutes (20 people) in which to reach the toilet. Urge fecal incontinence was reported daily by 32 people and more than weekly by another 17. Thirty-two had experienced daily passive soiling, another 15 at least weekly. For 38 people incontinence was to solid stool; 44 reported a large amount of leakage. Forty-seven always wore a pad; however, a few people reported infrequent incontinence only.

When asked "how much did you feel that your bowel control restricted your life before your stoma?" 45 replied "a great deal," 17 said "quite a lot," 4 replied "a little," and three "not at all." Asked to rate bowel control before the stoma on a 0 to 10 scale, the median rating was zero (range, 0–10; 1 nonresponder). Current rating of ability to live with the stoma now (Fig. 1) was negatively correlated with rating of previous bowel control ( $P = 0.055$ , Pearson correlation), *i.e.*, the lower previous bowel control was rated on a 0 to 10 scale, the greater the rated ability to live with the stoma now.

When asked to describe how bowel control had restricted life, many commented in great detail, with a variety of strongly negative comments. Life had focused around toilets for many, others were virtually housebound. Most mentioned restrictions to social, personal, and work life because of fecal incontinence.

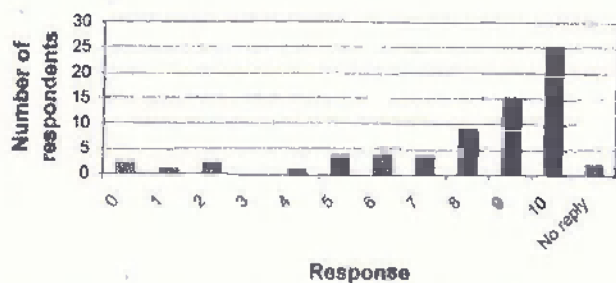


Figure 3. Please rate how satisfied you are with having the stoma.

Five described life as a "nightmare"; comments such as "I absolutely hated myself" and "sheer hell" were common.

### Overall Feelings About the Stoma

Figure 3 shows the response to the question "please rate how satisfied you are with having the stoma." The median response was 9 (range, 0-10). There was no

ference in rating of satisfaction with the stoma between those who reported a current major disease or disability and those who did not.

Three questions, with five options for answers, were asked about the decision to have a stoma:

1. Now that you know everything that having a stoma operation involves, would you decide to have it again?
2. If a friend had fecal incontinence that treatment had not improved, would you recommend a stoma to him or her?
3. If it were possible to go back to how you were before your operation, would you choose to have your stoma closed?

The answers are shown in Table 2 (1 person did not answer these questions).

Respondents were asked the question "compared when you were incontinent, how much change has having a stoma made to your overall quality of life?" A Likert scale from -5 to +5 was given for the response, in which -5 = much worse, 0 = same, +5 = much better. The median rating was +4.5 (range, -5 to +5; Fig. 4).

Comparing the response to the two questions about perceived effect on quality of life with a stoma now and with incontinence previously, there was a significant difference ( $P = 0.008$ , Fisher's exact test, Fig. 5).

### Quality of Life

Sixty-eight people completed the SF-36 questionnaire. Results are shown in Table 3. On all subscales

except mental health, respondents scored well below United Kingdom population norms. However, as stated above, the respondents had a variety of other health problems and disabilities in addition to a stoma. The responses to the condition-specific questionnaire are given in Table 4 (68 replies). The final column shows the percentage of respondents who answered a question who ticked "not at all," or "a little" (excluding those who answered "don't do it for other reasons"). More than one-half of respondents ticked these options on all questions.

### Anxiety and Depression

Sixty-six people completed the Hospital Anxiety and Depression scale. On the 21-point scale (21 = maximum score), the median anxiety score was 6 (range, 0-18); the median score for depression was 2.5 (range, 0-20). The original authors suggested that a score of 0 to 7 denotes "non-case," 8 to 10 "borderline," and 11 to 21 as "case" for each condition (Table 5).<sup>5</sup>

### DISCUSSION

The respondents in this study were a self-selected group, and it is not known whether they are representative of all people who chose a stoma for incontinence. People who are members of a support organization might be more likely to have problems (hence joining) or might get support and practical information from membership, helping adaptation.<sup>6</sup> Patients operated at a specialist hospital also may not be representative.

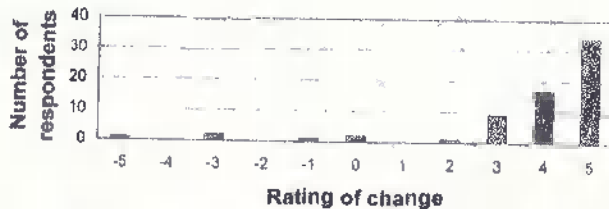
The present study did not find a universally positive response, but the majority did feel that the stoma was of benefit. Some of those with the most problematic stomas were those who seemed to not accept it, but this was not always the case. A few seemed to hate it. It is not known if there were any predictive factors for this.

Less than 10 percent of all stomas are formed for reasons other than specific bowel pathology.<sup>7</sup> To our knowledge, no previous study has looked at the response of people to having a stoma formed to manage bowel function (as opposed to removing diseased bowel), with the exception of people after spinal cord injury. Studies of spinal cord injury patients who had a stoma formed because of bowel management problems have found reduced time taken for bowel care,

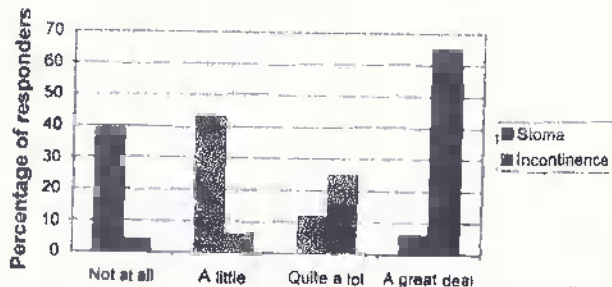
**Table 2.**  
Decision to Have a Stoma

	Have Stoma Again?	Recommend to a Friend?	Have Stoma Closed?
Definitely not	4 (6)	2 (3)	53 (78)
Probably not	1 (1)	1 (1)	5 (7)
Don't know	6 (9)	8 (12)	3 (4)
Probably yes	12 (18)	16 (24)	5 (7)
Definitely yes	45 (66)	41 (60)	2 (3)

Data are numbers (N = 68 responses) with percentages in parentheses.



**Figure 4.** How much change has having a stoma made to your quality of life?



**Figure 5.** Perceived effect on quality of life.

improved quality of life, and with no patients wanting the stoma closed.<sup>8-11</sup>

Many of the respondents had experienced practical problems with their stoma. It is not known whether referral to a stoma care nurse could have resolved any of the current problems. A copy of the study report was sent to all respondents, with the suggestion that they might seek further professional help if needed. Complications have been found to be common, affecting more than two-thirds of people with a temporary colostomy.<sup>12</sup> In a study of 391 ostomists, 40 percent of colostomists reported skin rashes, 36 percent bag leakage, 40 percent a bulge next to the stoma, 41 percent with problems making bags adhere, and 80 percent some change in lifestyle.<sup>13</sup> Poor adaptation to a stoma is correlated with complications.<sup>14-16</sup> However, the two patients who had subsequent short-bowel syndrome and the most major complications both felt that they would decide to have the stoma again.

Other studies have reported hernia rates from 11 to

**Table 3.**  
SF-36 Scores

SF-36 Subscale	Respondents' Mean	Population Norms
Physical functioning	49.4	88.4
Role physical	37.7	85.8
Bodily pain	53	81.5
General health	54.8	73.5
Vitality	46	61.6
Social functioning	67.5	88
Role emotional	66.5	82.9
Mental health	71.6	73.8
Health transition (median)	60	X

For all subscales except HT, 100 is the optimum score. A score of 60 on HT indicates a stable state of health (no norms available).

48 percent.<sup>7,15,17-20</sup> Forty-two percent of the current sample had experienced a hernia, but some were as yet not up to ten years after surgery, so it is not possible to compare results. A higher rate than for other stoma patients might be because of a common etiology with the original incontinence (for example muscle weakness or poor collagen). People with fecal incontinence have been found to have an above average body mass index,<sup>5</sup> and it is possible that obesity contributes to both a risk for incontinence and herniation after stoma formation.

Many respondents experienced anal mucus leakage, necessitating wearing a pad or proctectomy. Possibly previously incontinent patients are more likely to be incontinent of any mucus produced. It might be thought that this leakage would mimic previous incontinence and detract from the advantage of having a stoma. However, very few people mentioned this as a specific problem.

Overall quality of life in terms of activities has been found to be good in most stoma patients,<sup>7</sup> with difference between those with a stoma and those with stoma-sparing operations not as significant as sometimes perceived by health professionals.<sup>21</sup> Overall quality of life, as measured by the SF-36, was well



Table 4.  
During the Last Four Weeks How Much Has Your Stoma Affected Your...? (N = 68 Replies)

	Not at All	A Little	Moderately	A Lot	Made it Impossible	Other Reasons	Missing	% "Not at All" or "A Little"
Social life	31	18	9	7	3	0	0	72
Eating with family or friends	40	13	5	7	3	0	0	78
Going shopping	44	8	10	2	1	3	0	80
Visiting friends or family	44	14	3	3	1	3	0	89
Physical or sexual relationship with partner	16	3	5	5	3	36	0	59
Staying away/holidays	35	8	8	5	3	9	0	73
Travel by car	54	4	4	3	1	2	0	88
Travel by public transport	38	9	2	5	2	12	0	84
Physical exercise/sport	19	10	3	4	9	23	0	64
Ability to walk	48	11	1	2	1	5	0	94
Ability to work	27	7	2	1	1	28	2	89
What chosen to eat	22	18	16	12	N/A	N/A	0	59
Way you dress	31	16	12	7	2	N/A	0	69
Ability to go places where you do not know where the toilets will be	27	12	9	14	3	2	1	60
Sleeping	38	16	6	5	1	2	0	82
Drinking alcohol	30	7	3	3	3	21	1	80
Attend religious activities	38	6	1	3	4	15	1	85
Restricted by fear of smell or embarrassment	35	18	5	9	N/A	N/A	1	79
Physical health	38	16	9	3	N/A	N/A	1	81
Mental health	37	18	6	6	N/A	N/A	1	82
Overall adverse effect	29	18	7	8	N/A	N/A	6	76

N/A = not applicable.

Table 5.  
HAD Category

	Noncase (0-7)	Borderline (8-10)	Case (11-21)
Anxiety	41 (62)	15 (23)	10 (15)
Depression	55 (83)	4 (6)	7 (11)

HAD = hospital anxiety and depression scale.

Data are numbers (N = 66 responses) with percentages in parentheses.

below population norms across all categories except mental health. However, nearly all felt that the stoma had improved their quality of life compared with when they were incontinent (Fig. 5). This implies that previous quality of life had been very poor, which may have been why the stoma was suggested, or there may be recall bias, or a need to "validate" the decision to undergo surgery by emphasizing how bad things were before. In addition, many respondents had other health problems. Whatever the reason, all but six reported that the stoma had made a positive difference to their life quality.

Respondents did not include a high proportion with severe anxiety or depression as measured by the HAD scale. People with depression may be less likely to volunteer for a study such as this, therefore, this may reflect a recruitment bias. Other studies of stoma patients have found depression rates up to 70 percent.<sup>22</sup> Patients undergoing surgery for rectal cancer have been found to be significantly more depressed if that surgery included formation of a stoma than after sphincter-preserving surgery (32 vs. 10 percent depressed)<sup>23</sup> and to experience a worse quality of life.<sup>24</sup>

A stoma has been found to be associated with a sense of loss of control.<sup>25</sup> However, participants in the present study had a different previous experience to those with a stoma for cancer, being incontinent previously. Because a stoma is created by a surgeon during an operation, this may legitimize the condition and enable it to be explained to others more easily than incontinence, which has been associated with guilt, shame, and a sense of self-blame.<sup>26</sup> Many mentioned "control" in comments, both the lack of control before surgery and the sense of improved control with a stoma.

Bekkers and colleagues<sup>15</sup> have found that a sense of self-efficacy is important in adapting and adjusting to life with a stoma. Amount of choice before surgery has been found to be positively correlated to adaptation to a stoma, with those undergoing elective surgery faring best.<sup>6</sup> The current patients might have

adapted well because they had positively opted for a stoma, rather than feeling compelled to have one by a life-threatening disease.

## CONCLUSIONS

In this retrospective study of self-selected people who had undergone formation of a colostomy to manage fecal incontinence, the overwhelming majority were positive about the stoma and the difference it had made to their life. A few had not adapted and disliked the stoma intensely. A prospective longitudinal study is needed to determine the true impact of stoma formation on people with severe fecal incontinence and to identify factors that might predict successful adaptation. In the mean time, health care professionals should at least discuss a stoma as an option with patients whose lives are restricted by fecal incontinence.

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