

Living with Stoma: Long-term Effects on Patients' Quality of Life

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Abstract

Introduction: Constructing end stoma is a recognized surgical option for management of anatomical anomalies and bowel dysfunctions. Yet, the long-term outcome for that creation is not known. For finding answer for the question on "the long term outcome for living with permanent stoma after five years of creation" we conducted this survey.

Objective: Patients have right to know about the possible adverse that may result after surgical operations before giving consent to proceed. However, the long-term outcome after the first five years after construction of end stoma has not been examined. This study is aimed at identifying these possible adverse.

Methods and patients: Members of the United Ostomy Association of America have been requested to complete online survey.

Results: Seventy-eight respondents took part in this survey. The diagnosis was ulcerative colitis in 33, Crohn's disease in 11, colonic perforations in 10, bowel tumors in 5, post-radiation severe bowel damage in 3, severe constipation in 4, and no diagnosis was given by further 4 participants. Two participants gave history of congenital malformations (Ehlers Danlos Syndrome and Imperforate anus respectively) Conditions, such as: intestinal obstruction, infected J pouch, diverticulitis, Familial Adenomatous Polyposis (FAP), Ovarian carcinoma and indeterminate colitis were diagnosed in one participant each. Out of the 33 ulcerative colitis patients, 25 identified their pre-operative abdominal pain as it was severe (75.8%) and this pain completely disappeared after surgical resection in 18 (72%). At analyzing the responses to question (3): (How do you feel in general?), it was found that those in the group with a longer elapsed time after diagnosis were more likely to feel better ($p=0.042$). But those in the older age group (>50 years) were more likely to feel worse ($p0.024$); Patients in the older age group (>50 years) tended to experience more pain after creation ($p=0.046$); Patients with a longer elapsed time after diagnosis (>5 years) were more likely to say no at answering question (7): (Has your treatment changed the way you see yourself as a man/woman?) ($p=0.039$) and to say no at answering question (8) (Has your treatment caused any change in your sexual functioning (sex life)?) ($p=0.007$) as well; this group of patients were more likely to enjoy the things they used to before conducting the disease ($p=0.025$); there were no significant statistical differences were found between those who presented with an established stoma of less than five years old and those with stomas of more than five years old.

Conclusion: Participants in the group with a longer elapsed time after diagnosis were more likely to feel better ($p=0.042$), to have better self-perception ($p=0.039$), to be more satisfied about their sexual performance ($p=0.007$), and to enjoy the things they used to before conducting the disease ($p=0.025$). However, the effect of self-perception on sexual act is significantly high in the two groups.

Keywords: Ileostomy; Colostomy; Bowel diseases; Surgery; Inflammatory bowel diseases cancer rectum; Permanent

Introduction

Constructing permanent ileostomy or colostomy is a surgical procedure that is usually undertaken for a number of conditions, some of them are due to congenital problems, such as anorectal malformations. But others are due to disorder or other reasons for failure to function: bowel neoplasia, inflammatory bowel diseases, severe idiopathic constipation, intestinal blockage or internal injury.

At operation, the bowel is diverted to empty through an opening (stoma) in the abdomen. The stoma permits the attachment of a changeable, watertight bag that fills with feces and is emptied manually. Some people are able to dispense with the bag and instead are able to irrigate on a routine basis and wear a small stomal cap over the stoma.

Surgeons are required to do counseling with patients prior to creating the stomas. However, our current knowledge lacks data on the long-term experience that patients could acquire with living with stomas after five years after the creation [1]. It has been proposed that patients could act and adapt themselves to the existence of a stoma better if their forthcoming problems were discussed with them properly before surgery [2]. What do individuals' sense of themselves

and others' perceptions of them and whether the time factor plays some role in changing their initial experience? What is the impact of managing a stoma on self-image and sexual/social relationships after short and long periods after surgery? For finding answers for these valuable questions and others, we communicated with the United Ostomy Association of America for seeking the board's acceptance for allowing their members to participate in a survey was designed for serving that purpose.

Objectives

The aim for conducting this survey is to find answers for the following questions:

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1. Are the patients' perception of themselves and others' perception of them fixed or changeable with time?

2. What is the influence of time on peoples' impression on the existence of stoma on self-image and sexual/social relationships?

Methods and Patients

A questionnaire was registered with the Monkey Survey website and became available for people through a link "http://www.surveymonkey.com/s/F97SPPW" Members of the United Ostomy Association of America were then requested to participate in the survey by communicating with this link, completing the questionnaire and then submitting the completed forms online.

Statistical Methods

"Continuous data are summarised as medians and ranges, with categorical data presented as numbers and percentages. Respondents were divided into two groups based on their age (<50 years or >50 years), time since diagnosis (<5 years or >5 years) and time since creation of stoma (<5 years or >5 years). In each case, comparisons of the two groups were performed using Mann-Whitney tests. PASW Statistics 18.0 for Windows (SPSS Inc., Chicago, Illinois) was used for all the statistical analyses."

Results

Seventy-eight respondents took part in this survey (Table 1). The diagnosis was ulcerative colitis in 33, Crohn's disease in 11, colonic perforations in 10, bowel tumors in 5, post-radiation severe bowel damage in 3, severe constipation in 4, and no diagnosis was given by further 4 participants. Two participants gave history of congenital malformations (Ehlers Danlos Syndrome and Imperforate anus respectively) Conditions, such as : intestinal obstruction, infected J pouch, diverticulitis, Familial Adenomatous Polyposis (FAP), Ovarian carcinoma and indeterminate colitis were diagnosed in one participant each (Table 2). The age at participation was less than 50 years old in 19 (mean 41.05 (22-49)) and it was equal to and more than 50 years old in 44 (mean 62.84 (50-81)) and 15 participants did not provide information about their DOB.

Resection of the diseased bowel mucosa succeeded to relieve abdominal pain in 28 out of the 33 patients with UC (84.8%), but such relief was not that much in subjects with Crohn's disease (6 out of 11 , 54.5%) and the least relief was recorded by the constipating patients (50%). Permanent stoma was constructed in five years or less after the diagnosis in 34 participants (43.6%) but the creation was undertaken after more than five years after diagnosis in further 37 participants and the timing of creation was not provided by other seven. Out of the 33 ulcerative colitis patients, 25 identified their pre-operative abdominal pain as it was severe (75.8%) and this pain completely disappeared after surgical resection in 18 (72%) (Table 3). At analyzing the responses to question (3) (Scheme 1): (How do you feel in general?), it was found that those in the group with a longer elapsed time after diagnosis were more likely to feel better (p=0.042). However, those in the older age group (>50years) were more likely to feel worse (p0.024). Patients in

Gender of the participants	Number
Females	33
Males	20
Not Given	25
Total	78

Table 1: Gender of the participants.

Disease or condition	Number of patients
Ulcerative colitis	28
UC+haemorrhage	02
UC+anal tumour	01
UC+metaplasia	01
UC+perforation	01
Total	33
Crohn's disease	11
Bowel tumours	05
Radiation	03
Ruptured colon/perforations	10
Severe constipation	04
Ovarian Carcinoma	01
FAP	01
Intestinal Blockage	01
Congenital	02
Diverticulitis	01
Not Given	04
J pouch infected	01
indeterminate colitis	01

Total number of patients are 78 (a patient with Ehlers Danlos syndrome presented with perforation).

Table 2: Reasons for construction.

the older age group (>50 years) tended to experience more pain after creation (p=0.046). Patients with a longer elapsed time after diagnosis (>5 years) were more likely to say no at answering question (7): (Has your treatment changed the way you see yourself as a man/woman?) (p=0.039) and were more likely to say (No) at answering question (8): (Has your treatment caused any change in your sexual functioning (sex life)?) (p=0.007) as well; this group of patients were more likely to enjoy the things they used to before conducting the disease (p=0.025); there were no significant statistical differences were found between those who presented with an established stoma of less than five years old and those with stomas of more than five years old.

In a question about whether the existence of stoma has affected the way that they are seeing themselves, 17 of the 34 female participants answered with "NO" (50%), two gave no response, but 14 responded positively (41.2%). 80% of the male participants responded negatively at answering the same question. However, 3 (15%) said "Yes" and one gave no response (Table 4). In this series, eleven patients with a history of Crohn's disease presented with end stoma. Their abdominal pain prior to surgery was categorized as severe by six (54.5%), moderate by further three (27.2%) and mild by the remaining two (19.3%). Six participants with Crohn's disease experienced no pain postoperatively (54.5%). However, pain persisted in the other five after surgery but to a lesser extent (45.5%). The persistence of pain did not interfere with patients' enjoyment of their lives as they were before conduction of the disease in three (Table 4).

Discussion

The Discussion Board of the UOAA has approved this study. For validating the dispensed questionnaire, a pilot study was conducted and copies were sent to members of the Association to complete. Thirteen members of the UOAA returned the forms after completion and none of them found any difficulty at answering the questions.

Data from the USA revealed [3] that the number of the discharged patients from hospitals with new permanent colostomies during the period between 2002-2007 was 44484 new colostomies per annum. However, the number of those discharged with permanent ileostomies

gender	age	disease	Length of stoma	Well being	Persistent Abdominal pain after hand	Duties/ incapability	Bad feeling of Body image	Social limitation	Enjoying life
F	50	constipation	3years	Slightly improved	severe→ mild	Yes	Yes	sometimes	Not quite so much
F	58	congenital	8years	Slightly improved	severe→ severe	Yes	Yes	sometimes	Only a little
F	24	UC	5years	Very well	moderate→ moderate	No	Yes	Always	Not quite so much
M	71	Depression	10	poor	moderate→ moderate	Yes	No Response	sometimes	Only a little
F	55	UC/ perforation	5years	Very well	severe→ nil	No	No	Never	Definitely as much
F	52	Bowel perforation	2 years						
F	52	UC	3years	Slightly improved	severe→ nil	No	Yes	sometimes	Hardly at all
F	26	UC	6years	Very well	severe→ nil	No	Yes	Rarely	sometimes
F	48	Constipation	2 years	Very well	severe→ nil	No	-----	Never	Definitely as much
M	62	Perforation	12 years	Very poor	moderate→ severe	No	No	Always	Hardly at all
F	46	Cancer rectum	5years	Very well	nil→ moderate	Yes	Yes	sometimes	Definitely as much
F	46	Crohn's disease	9years	Very well	moderate→ nil	No	-----	sometimes	Not quite so much
M	56	Radiotherapy for bowel cancer	3years	Very poor	severe→ moderate	-----	Yes	Always	Hardly at all
F	40	Bowel cancer	4years	lightly improved	no	no	yes	Always	Hardly at all
F	62	MS	15 years	Very well	moderate→ nil	no	yes	Never	Definitely as much
M	70	UC	35	Very well	severe→ nil	no	no	Rarely	Definitely as much
M	75		23	Very well	moderate→ nil	no	no	Rarely	Definitely as much
F	71	Bowel cancer	5months	Very well	no	no	no	Rarely	Definitely as much
M	54	UC	6 years	Very well	severe→ nil	Yes	Yes	Rarely	Not quite so much
F	74	Ruptured colon	3years	Very well	no→ mild	no	Yes	Rarely	Definitely as much
F	48	Crohn's disease	5 years	Very well	mild→ nil	no	no	Rarely	Definitely as much
M	59	UC	22 years	Very well	severe→ nil	no	no	Always	Only a little
M	68	UC	8years	weak	moderate → nil	no	Yes	sometimes	Definitely as much

Table 3: The effect of different factors in subjects who sensed changes in their sexual act after surgery.

< 5 years	≥ 5 years
Disease: 4/7	Disease: 5/15 (30%)
Body Image: 2/7	Body Image: 5/15 (30%)
Age: 2/7	? Sexual problem: 3/15 (20%)
	Age: 3/15 (20%)

Table 4: The possible role of different factors in causing the sensed changes in sexual act after surgery.

during the same period was 13114 per annum. This figure increased by ~ 10% to become 16974 new ileostomies in 2008 [3].

Reasons for constructing permanent stomas and its necessity are quite different in different diseases. For example, abdomino- perineal removal and an end colostomy is considered to be as a principal indication for the treatment of cases of rectal carcinoma which is either too low or too bulky and it is also advised to be considered in cases of fixed lower rectal carcinoma with a history of radiotherapy [4]. However, in patients with Crohn's disease, it has been estimated [4] that almost half of all patients who usually require surgery for large bowel Crohn's disease will ultimately require a proctectomy and end stoma. In the majority of patients, this will involve a proctocolectomy and end ileostomy. In many instances, the inflammatory process involves the rectum at the onset and complications, such as recto-vaginal fistula, severe rectal fibrosis, or aggressive perianal sepsis demand total proctocolectomy and ileostomy as the initial surgery. In another group, secondary proctectomy may be needed because of progressive rectal involvement or the occurrence of recurrence after sphincter-conserving procedure.

The impact of such construction on patients' quality of life was the subject of investigation in a number of published reports

[5-18]. In a recent published article, for instance, Brennan et al. [5] examined the effect of ileoanal pouch anastomosis on ulcerative colitis patients' quality of life and compared the results in them with those of individually matched patients on whom end ileostomy was created by the use of validated questionnaires (short-form 36 version II questionnaire, inflammatory bowel diseases questionnaire) and a few additional questions. The outcome of this survey was that restorative proctocolectomy was associated with significantly better perception of body image than with permanent stoma. Although quality of life in general was similar in both groups, patients with a pouch had more long-term complications than patients with an ileostomy within the same period of time (52.6% versus 26.3%) The median number of stages for pouch construction was two, compared to a median of one stage for an ileostomy (p<0.0001). This means that creation of ileo-anal pouches has better perception of personality but worse clinical consequences than that of end stomas. This better perception of personality in the first group than in the second group is likely to be related to other co-factors. Bosseman, for example, suggests that disease-acceptance by the patients plays significant role in the establishment of the above conclusion [6].

If Bosseman's findings were true, the results of studying the effect of creating end stomas on patients' quality of life would be expected to be better in those in whom the creation was conducted a longer time ago.

The analysis of the collected answers from the participants in this survey demonstrated that at answering question (3): (Figure 1), it was found that those in the group with a longer elapsed time after diagnosis were more likely to feel better (p=0.042); to say no at answering question (7) (p=0.039); to say (No) at answering question (8) (p=0.007); and

3. How do you feel in general?	
Very well ()	79.2%
Slightly improved ()	8.3%
Poor ()	2.8%
Very poor ()	6.9%
Other (please specify)	8.3%

4. Do you experience abdominal pain?	
	Response Percentage
None ()	64.8%
Mild ()	18.3%
Moderate ()	15.5%
Severe ()	5.6%

5. Did you ever have abdominal pain before treatment?	
	Response Percentage
No ()	9.9%
Mild ()	9.9%
Moderate ()	28.2%
Severe ()	56.3%

6. Has your treatment interfered with you being a mother/ wife/ husband/ father?	
Yes ()	15.2%
No ()	84.8%

7. Has your treatment changed the way you see yourself as a man/ woman?	
	Response Percentage
Yes ()	39.1%
No ()	62.3%

8. Has your treatment caused any change in your sexual functioning (sex life)?	
	Response Percentage
Yes ()	40.3%
No ()	54.2%
Other (please specify)	8.3%

9. Do you experience any social limitations?	
	Response Percentage
Never ()	36.1%
Rarely ()	27.8%
Sometimes ()	26.4%
Always ()	11.1%

10. Do you still enjoy the things you used to enjoy?	
	Response Percentage
Definitely as much ()	62.5%
Not quite so much ()	12.5%
Only a little ()	11.1%
Hardly at all ()	6.9%
Other (please specify)	13.9%

Scheme 1: The Analysis of the results.

were more likely to enjoy the things they used to before conducting the disease ($p=0.025$).

Yet, the persistence of symptoms after surgery and/ or the addition of further post-operative adverse may play significant role in patients' perception of themselves. For excluding these possible factors, we studied patients' perception further in those who answered "yes" to

question "8". In this assessment, we used the existence of abdominal pain after surgery as signal for illness or adverse, answers to questions on well-being, & capability to do domestic duties as guidance for the general condition of this subgroup of participants and answers to questions "9" & "10" as other co-factors for assessing whether personal perception played significant role in sexual performance. The results of this assessment are recorded in Table 4.

In general, we can conclude that personal perception played significant role at practicing sex (~ 30% each). Yet, proper pre-operative counseling of the patients with their spouses may play significant role towards better personal perception.

Conclusion

Participants in the group with a longer elapsed time after diagnosis were more likely to feel better ($p=0.042$), to have better self-perception ($p=0.039$), to be more satisfied about their sexual performance ($p=0.007$), and to enjoy the things they used to before conducting the disease ($p=0.025$). However, the effect of self-perception on sexual act is significantly high in the two groups. Proper pre-operative counseling of the patients and spouses is a necessity for managing this adverse.

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