Sexual problems among married ileostomists

Survey conducted by The Ileostomy Association of Great Britain and Ireland

W. R. BURNHAM, J. E. LENNARD-JONES, and B. N. BROOKE
From St Mark’s Hospital, London, and St George’s Hospital, London

SUMMARY  The Ileostomy Association of Great Britain and Ireland has conducted a survey to assess the incidence and nature of sexual problems among a one in 10 sample of its membership. The analysis was restricted to married ileostomists; of those aged up to 45 years at the time of operation 16% had married and 23% had had children after the operation. The majority had adapted well to the ileostomy, and this appeared true also for the spouse. However, 12% of those who replied ascribed marital tension, unhappiness, or even separation, to the presence of the stoma. There was no evidence of sexual dysfunction from the construction of an ileostomy without rectal excision. After rectal excision nearly one-third of men reported sexual dysfunction, the frequency and severity of which was related to the age at operation. Up to the age of 45, one of 88 men developed complete erectile impotence and 17 partial dysfunction; over this age five of 30 men developed complete and 11 partial erectile impotence. One-third of women reported some dyspareunia after rectal excision.

Concern has been expressed within the Ileostomy Association that sexual difficulties may be more common than is usually supposed when one partner of a marriage has an ileostomy. The National Executive of the Association therefore decided to undertake an inquiry among its membership to ascertain if this is so. With the information obtained it was hoped that helpful advice could be given to ileostomists, and to patients before and after operation, either by personal discussion or in the form of a pamphlet. It was also hoped that the results would remove uncertainty about the size of the problem and that the data would bring the matter to the attention of those concerned in the treatment of patients requiring an ileostomy and in their subsequent medical care.

A small committee was set up to plan and carry out the survey. An inquiry form was designed with both specific questions and sections in which the recipient was invited to comment on personal difficulties and any means found for overcoming them; most of the questionnaire was the same for both sexes but the final section differed for men and women. To obtain a representative sample the questionnaire was sent by post to every tenth member between the ages of 18 and 65 years on the membership list of the Ileostomy Association. A covering letter emphasised that the aim of the survey was to help ileostomists and that individual replies would be anonymous and regarded as strictly confidential.

Results of survey

Of 540 questionnaires sent out, 376 (70%) were returned. Of these, 316 were completed by members of the Association who understood that their ileostomy had been performed as a treatment for colitis (ulcerative colitis or Crohn’s colitis). An opportunity was provided for the form to be returned uncompleted if the recipient wished to do so; 43 ileostomists (17 men and 26 women) followed this course. Seventeen forms were excluded from subsequent analysis for the following reasons: returned, address unknown (seven), operation performed for other disease or no ileostomy (eight), returned too late for inclusion (two).

Of the 316 forms completed by ileostomists treated for colitis, 175 were returned by married women, 128 by married men, 13 by single men, and
none by single women. The analysis has been restricted to married ileostomists.

**SOCIAL DATA**

**Age**
The age distribution of the married ileostomists who completed the questionnaire is shown in Table 1. It will be seen that the majority were between 26 and 55 years.

**Date of marriage in relation to ileostomy**
Twenty-four of the 128 men and 21 of the 175 women married after construction of the ileostomy.

**Parenthood**
Thirty-seven of 96 men and 19 of 148 women, aged up to 45 years at the time of operation, became parents.

**PHYSICAL DIFFICULTIES CAUSED BY PRESENCE OF A STOMA**
Only 10 of 128 men and 14 of 175 women found that the presence of a stoma made intercourse difficult. Fears of damage to the stoma, leakage from the bag or displacement of the appliance, were about twice as common among the women as among the men, whereas a greater proportion of the men found that the bag was a hindrance. An important aim of the survey was to ask ileostomists about methods they had developed of overcoming any difficulties. The most frequent comment was that the bag should be emptied before intercourse and some ileostomists suggested that the volume entering should be reduced as far as possible by slight dietary restriction. Many also suggested that a suitable garment or girdle should be worn to fix or disguise the appliance.

**EMOTIONAL REACTIONS TO STOMA**
About 90% of both sexes said that they were able to discuss sexual problems freely with their partner. Whereas about 30% of ileostomists said that the stoma embarrassed them, only 8% of their wives and 2% of their husbands were said to feel the same. About half the ileostomists felt less attractive sexually but, again, a much smaller proportion of their partners (9% of wives and 6% of husbands) were said to share this view. The results did not suggest any change in libido for either sex after operation. An opportunity was given for the ileostomist to apply one of a series of four adjectives to the stoma, or to supply a different adjective of their choice. Results, which were very similar for men and women, are displayed in Table 2. It will be seen that about 5% of the ileostomists regarded the stoma as ‘repulsive’ and another 12% regarded it as ‘unpleasant’. Further analysis showed no obvious correlation between those who regarded the stoma as unpleasant or repulsive and those whose marriage broke up or who experienced partial or complete erectile or ejaculatory impotence.

Three men (2%) and four women (2%) attributed marital breakdown with separation to sexual difficulties consequent upon the ileostomy; none of these men was impotent. A further 10 men (8%) and 21 women (12%) reported that difficulties caused by the stoma had been responsible for unhappiness or tension with their partner; seven of these 10 men had complete or partial loss of sexual function.

**EFFECT OF OPERATION ON SEXUAL FUNCTION**
Since removal of the rectum may have important effects on sexual function, questions were asked about the effects of ileostomy alone without removal of the rectum, and about the effects of ileostomy and removal of the rectum. As the two procedures may be undertaken at different times, some of the ileostomists were able to answer both sets of questions.

**Male ileostomists with intact rectum**
The replies of the 42 men who have, or have had, an ileostomy without removal of the rectum revealed no evidence that ileostomy without rectal excision affected sexual function.

<table>
<thead>
<tr>
<th>Age (yr)</th>
<th>18-25</th>
<th>26-35</th>
<th>36-45</th>
<th>46-55</th>
<th>56-65</th>
<th>&gt; 65</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>3</td>
<td>37</td>
<td>39</td>
<td>33</td>
<td>16</td>
<td>0</td>
<td>128</td>
</tr>
<tr>
<td>Women</td>
<td>4</td>
<td>58</td>
<td>40</td>
<td>60</td>
<td>12</td>
<td>1</td>
<td>175</td>
</tr>
</tbody>
</table>

**Table 2 Adjectives chosen or supplied by ileostomists to describe stoma**

<table>
<thead>
<tr>
<th>Adjective chosen</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Natural opening&quot;</td>
<td>51</td>
<td>57</td>
</tr>
<tr>
<td>&quot;Unsightly&quot;</td>
<td>22</td>
<td>37</td>
</tr>
<tr>
<td>&quot;Unpleasant&quot;</td>
<td>14</td>
<td>24</td>
</tr>
<tr>
<td>&quot;Repulsive&quot;</td>
<td>6</td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adjective(s) supplied</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embarrassing, vulnerable, inconvenient, nuisance, inhibiting, unfeminine</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Acceptable, tolerable, necessary, life-saving, functional, etc.</td>
<td>18</td>
<td>29</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>No answer</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>
Sexual problems among married ileostomists

Male ileostomists after removal of rectum
The responses to the same questions by the 118 men in whom the rectum has been removed are shown in Table 3. It will be seen that, unlike the replies after ileostomy alone, a proportion of the men described loss of sexual function not previously experienced; a few men reported improvement in function. Thus, six of the 118 had total erectile impotence, 12 could achieve only partial erection, and 21 found it difficult to maintain erection. Nine of the 118 found ejaculation impossible after operation. Diminution of sexual function was related to the age at the time of operation, as shown in Table 4. Up to the age of 35, the incidence was 15%; none developed complete erectile impotence, but five of 61 patients experienced partial erectile impotence and four failure of ejaculation. Over the age of 35 sexual impairment occurred in 44% and over the age of 45 in 53% of patients. Five of 30 men over 45 developed complete and 11 partial erectile impotence.

Table 3 Sexual function in men before and after rectal excision

<table>
<thead>
<tr>
<th>Presence of erection</th>
<th>Rectal excision</th>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>108</td>
<td>87</td>
<td></td>
</tr>
<tr>
<td>Partial</td>
<td>3</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Absent</td>
<td>1†</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>No answer</td>
<td>6</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Maintenance of erection</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintained</td>
<td>103</td>
<td>89</td>
<td></td>
</tr>
<tr>
<td>Poorly maintained</td>
<td>62</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>No answer</td>
<td>9</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Ejaculation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Possible</td>
<td>109</td>
<td>101</td>
<td></td>
</tr>
<tr>
<td>Impossible</td>
<td>1</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>No answer</td>
<td>8</td>
<td>7</td>
<td></td>
</tr>
</tbody>
</table>

*Two of these patients reported improvement after rectal excision.
†Improved to partial erection after rectal excision.
‡Five of these patients reported improvement after rectal excision.

Female ileostomists with intact rectum
Of the 57 women in this group, 15% experienced a new discomfort on intercourse after the operation. There was little difference in the frequency with which orgasm was experienced before (56%) or after (63%) operation.

Female ileostomists after removal of rectum
Among these 165 women, 41 experienced some discomfort on intercourse before removal of the rectum; after operation, 54 experienced a new discomfort. The proportion who experienced orgasm and pleasurable sensation tended slightly to increase.

Sources of advice on sexual problems for ileostomists
About 40% of those replying had been able to discuss sexual problems with a doctor, and a very small proportion had turned to the Ileostomy Association and other sources; only 7% felt they received helpful advice from any source.

Discussion
The sample of the Ileostomy Association membership on which this survey is based was chosen in such a way that factors which might influence the result were excluded as far as possible. The sample covered the whole of Great Britain and Ireland, the age range was wide, and names were chosen in strict numerical order without reference to the person’s marital status. The overall return of 70% of the questionnaires was satisfactory but the replies, not unexpectedly, were limited almost entirely to married ileostomists. Frankness in answering the questions was encouraged by the fact that it was organised by ileostomists for their mutual benefit.

Although it is recognised that the quality of life after construction of an ileostomy is good in terms of work and recreation (Daly and Brooke, 1967), it is not known whether the stoma decreases the likelihood of marriage. The results from this series of married ileostomists show that a fifth of the men and one in eight of the women were unmarried at the time of their operation. Data from St Mark’s Hospital show that 20 out of 27 unmarried women up to 30 years of age at the time of ileostomy married later (J. K. Ritchie, 1976, personal communication), providing further evidence that an ileostomy is no bar to marriage.

With regard to parenthood, the figures for this survey are at least as good and in some cases better than previous studies. Stahlgren and Ferguson (1958) found that two of 35 women became pregnant and that nine of 14 men under 49 years of age fathered children after a proctocolectomy for ulcerative colitis. In Daly and Brooke’s series (1967),
eight of 62 women ileostomists became pregnant and delivered healthy children. However, 10 other women with normal periods under 40 years of age were infertile and three of them, out of four investigated, were found to have blocked Fallopian tubes. Hudson (1972) has emphasised that, as long as informed medical supervision of the labour is provided, pregnancy holds no special dangers and that vaginal delivery is not only usually possible, but sometimes preferable to a Caesarean section.

There are no data available from previous studies to indicate the incidence of mechanical difficulties caused by the presence of a stoma and appliance during sexual intercourse. This survey indicates that less than 10% of married ileostomists experience such difficulties. The use of a garment or girdle to fix or disguise the appliance/stoma and emptying of the bag before intercourse were frequently mentioned but no particular make or type of appliance appeared more convenient than others. Some ileostomists found a change in their normal position for intercourse helpful but most did not find this necessary.

About 10% of ileostomists said that the stoma resulted in 'tension' within the marriage. Analysis shows that seven of the 10 men who made this statement had reduced or absent sexual function after rectal excision. About 2% of men and women attributed breakdown of their marriage to the presence of the stoma. It is, of course, possible that in some cases the marital separation was in part or mainly due to other factors.

A small proportion of ileostomists found the stoma unpleasant or repulsive. Some typical comments of those who expressed strong feelings were 'I feel a recluse, without a social life', 'I feel less effective as a man and would not expect a woman to marry me', 'I feel less feminine, disfigured, and cannot bear my partner to come into contact with the bag'. It will be interesting in due course to compare the findings in this survey with the reactions of patients to a continent ileostomy without a protruding stoma or need for an appliance (Kock, 1973).

Sexual function was unchanged in the men and women in this series who underwent a colectomy and construction of an ileostomy, without rectal excision. The overall incidence of sexual dysfunction in men after rectal excision was 29%, 5% of men developing total erectile impotence. Some of the men with initial postoperative dysfunction noted improvement over the next two years. These figures take no account of age which this survey, in common with others, has shown to be an important factor. Thus, among men aged up to 45 years at the time of rectal excision, the incidence of complete erectile impotence was 1% and of partial sexual dysfunction was 18%; whereas in men aged over 45 years at the time of operation, 17% developed complete erectile impotence and 37% experienced some dysfunction. This figure of 17% may be compared with the figure of 7·6% for impotence among men at the age of 55 years found by Kinsey and his colleagues in their population survey (1948).

There have been a number of other studies of sexual function among men who have had a proctocolectomy and ileostomy for colitis. The largest study up to now has been that of Daly and Brooke (1967), who found complete impotence in six of 100 men and partial impairment in an additional five patients. May (1966) interviewed 46 men and reported that 35 had normal function, three temporary dysfunction, and eight permanent impairment of varying degree, three of whom were completely impotent. Watts et al. (1966) found some permanent impairment of sexual function among 11 of 41 men; six of eight patients over the age of 50 years became totally impotent, as compared with only one of 33 younger men. Donovan and O'Hara (1960) found two patients with impotence in a series of 19; Stahlgren and Ferguson (1958) found that five of 25 men interviewed had some sexual dysfunction after operation. Thus, the overall figure of 5% for complete erectile impotence in the present series, which is the largest to date, is comparable with the figures in these other series.

Trauma at operation is clearly an important aetiological factor in subsequent sexual dysfunction and surgeons take great care to avoid dividing pelvic autonomic nerves when removing the rectum for inflammatory bowel disease. It has been suggested that improved surgical technique or a particular surgeon's greater experience could minimise the risk (Daly and Brooke, 1967), especially as bilateral damage is required to produce impotence (Lee et al., 1973). However, at least three surveys (May, 1966; Watts et al., 1966; Daly and Brooke, 1967) describe results among patients who had been operated on by surgeons with both interest and special experience in gastrointestinal surgery and the findings were similar to those in this nationwide series. Innovations in methods for removal of the rectum, with the aim of avoiding damage to the perirectal tissues have been introduced by Lee and Dowling (1972), and Lyttle and Parks (1976). The preliminary results are encouraging but the effects of these procedures on sexual function, especially in older men, have not yet been fully evaluated.

In comparison with studies in men, there have been relatively few investigations of sexual dysfunction after ileostomy in women. Stahlgren and Ferguson (1958) studied 26 women and found no change in 23, improvement in one, and difficulties in two. The
main difficulty encountered by women studied in the present series was dyspareunia, presumably the result of pelvic scarring. It is of interest that the study of Grüner et al. (1975) of ileorectal anastomosis in ulcerative colitis showed that more than half of the 21 women in their series between 16 and 50 years of age had dyspareunia. This was attributed to rectal inflammation. It appears therefore that ileorectal anastomosis may not carry the immunity from postoperative sexual dysfunction that might be supposed.

A disquieting feature of this survey was the fact that those who went to their doctor or surgeon for advice on sexual matters often felt that they received no help. The Ileostomy Association, aware of the needs of some of its members, has produced a pamphlet based on the results of this survey, and plans to develop an advisory service. It is hoped that this report will provide factual data on which to base advice to patients.

We thank Miss S. J. Mallett for her great help in the preparation of this paper, and Mr S. Evans and Mr D. Guppy of the London Hospital Medical College for their help with the computer analysis of some of the data. This study was organised by the Ileostomy Association of Great Britain and Ireland, and we thank them for permission to publish the data. W. R. B. is in receipt of a Research Grant from the St Mark’s Research Foundation.

References


Sexual problems among married ileostomists. Survey conducted by The Ileostomy Association of Great Britain and Ireland.

W R Burnham, J E Lennard-Jones and B N Brooke

Gut 1977 18: 673-677
doi: 10.1136/gut.18.8.673

Updated information and services can be found at:
http://gut.bmj.com/content/18/8/673

These include:

Email alerting service
Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Notes

To request permissions go to:
http://group.bmj.com/group/rights-licensing/permissions

To order reprints go to:
http://journals.bmj.com/cgi/reprintform

To subscribe to BMJ go to:
http://group.bmj.com/subscribe/