Colostomy Impact Score
Differences in perception between healthcare personnel and patients

By

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Disclosure

- I have no disclosures
Background

- Surgery for colorectal cancer results in a planned permanent stoma in 10–30% of the patients\(^{(1-2)}\).

- The overall complication rate after stoma surgery varies from 21 to 70%\(^{(3)}\).

### The Colostomy Impact Score

<table>
<thead>
<tr>
<th>Question</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you experience embarrassing smells from your stoma-bag?</td>
<td></td>
</tr>
<tr>
<td>☐ No, never</td>
<td>0</td>
</tr>
<tr>
<td>☐ Yes, less than once a week</td>
<td>0</td>
</tr>
<tr>
<td>☐ Yes, at least once a week</td>
<td>2</td>
</tr>
<tr>
<td>Do you experience seepage of faeces under the sticking plaster?</td>
<td></td>
</tr>
<tr>
<td>☐ No, never</td>
<td>0</td>
</tr>
<tr>
<td>☐ Yes, less than once a week</td>
<td>2</td>
</tr>
<tr>
<td>☐ Yes, at least once a week</td>
<td>4</td>
</tr>
<tr>
<td>What is the consistency of your faeces?</td>
<td></td>
</tr>
<tr>
<td>☐ Hard and lumpy</td>
<td>8</td>
</tr>
<tr>
<td>☐ Formed and soft</td>
<td>0</td>
</tr>
<tr>
<td>☐ Mushy</td>
<td>3</td>
</tr>
<tr>
<td>☐ Watery</td>
<td>6</td>
</tr>
<tr>
<td>☐ Variable</td>
<td>6</td>
</tr>
<tr>
<td>Do you ever experience pain in and around the stoma?</td>
<td></td>
</tr>
<tr>
<td>☐ No, never</td>
<td>0</td>
</tr>
<tr>
<td>☐ Yes</td>
<td>5</td>
</tr>
<tr>
<td>Do you experience any skin problems around your stoma?</td>
<td></td>
</tr>
<tr>
<td>☐ No, never</td>
<td>0</td>
</tr>
<tr>
<td>☐ Yes</td>
<td>4</td>
</tr>
<tr>
<td>Have you noticed a bulge around the stoma?</td>
<td></td>
</tr>
<tr>
<td>☐ No</td>
<td>0</td>
</tr>
<tr>
<td>☐ Yes, I have a small bulge (under 10 cm)</td>
<td>2</td>
</tr>
<tr>
<td>☐ Yes, a I have a larger bulge (over 10 cm)</td>
<td>7</td>
</tr>
<tr>
<td>Who manages your stoma care?</td>
<td></td>
</tr>
<tr>
<td>☐ I do it all myself</td>
<td>0</td>
</tr>
<tr>
<td>☐ I need support and instruction</td>
<td>8</td>
</tr>
</tbody>
</table>

**Interpretation:**
- 0-9: Minor Colostomy Impact
- 10-38: Major Colostomy Impact

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**Colostomy Impact Score**

Patient derived score

From 17 items of the basic stoma questionnaire (BSQ)

7 questions with 12 weighted value responses.

0-9 Minor impact

10-38: Major Colostomy Impact
Aim

Using the patient-derived CI score as a reference, the aim of this study was to detect differences in the perception of the relative impact of colostomy-related problems on QoL between patients and healthcare professionals using the CIS.
Recruitment of the healthcare personnel:

- Centers of collaborative research:
  - SL and PC.
  - 14 centers.
  - Consultants, trainees.

- ASCN UK:
  - The Association of Stoma Care Nurses UK.
  - Stoma nurses.

- EuroSurg:
  - Medical student network.
Survey setup

- The healthcare participant first received an email with an invitation letter, which also explains the study.
- After they had agreed to participate, they were given a link to the survey where they should complete a few background questions about their profession, years of experience, country of practice and whether they had previously seen the CIS.
Results

ASCN UK
Centres of collaborative research
EuroSurg Students

Participants
$n = 157$

Excluded (had previously seen the CIS)
$n = 1$

Completed part 1
$n = 156$

Consultants
$n = 28$
(17.9%)
Trainees
$n = 31$
(19.9%)
Stoma nurses
$n = 55$
(35.3%)
Ward nurses
$n = 10$
(6.4%)
Medical students
$n = 32$
(20.5%)

Excluded (incorrect or incomplete part 2)
$n = 30$

Completed part 2
$n = 126$

Consultants
$n = 26$
(20.6%)
Trainees
$n = 29$
(23.0%)
Stoma nurses
$n = 33$
(26.2%)
Ward nurses
$n = 9$
(7.1%)
Medical students
$n = 29$
(23.0%)
157 respondents from 17 countries all over the world.
Task 1

Selection of the colostomy related problems
Selection of items (Task one)

- By using the same 17 colostomy-related problems presented to the patients during the development of the CI score in the same order.
- Participants were asked to choose the seven that - in their opinion - would have the greatest negative impact on patients with a colostomy.
**Task one outcomes**

Frequency of item selection.

Number of correct items in the original CI score

chi square test was used to compare between different professions
### Results

<table>
<thead>
<tr>
<th>No of correct selections</th>
<th>Stoma nurse</th>
<th>Consultant</th>
<th>Trainees</th>
<th>Ward nurse</th>
<th>Student</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>55</td>
<td>28</td>
<td>31</td>
<td>10</td>
<td>32</td>
<td>156</td>
</tr>
<tr>
<td>≥ 5 correct selection</td>
<td>36 (65.5%)</td>
<td>15 (53.6%)</td>
<td>21 (67.8%)</td>
<td>5 (50%)</td>
<td>12 (37.5%)</td>
<td>89 (57.1%)</td>
</tr>
<tr>
<td>P value</td>
<td>0.293</td>
<td>0.829</td>
<td>0.352</td>
<td>0.01</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*No sig. difference between the 5 professions, P value: 0.079*
Results (Task one)

1. Embarrassing smells
2. Seepage under plaster
3. Frequency of changing stoma bag
4. Skin condition around the stoma
5. Bulge around the stoma
6. Pain management around stoma
7. Consistency of stool
8. Irrigation of stoma
9. Frequency of changing flange
10. How faeces come out of the stoma
11. Stoma becomes lower
12. Do you take anti-diarrheal medications?
13. Plug use for stoma

All Participants
Stoma nurses
Task 2
Scoring and ranking the responses
Once part one was completed, the next page opened up with no return back option.

The original CI score with the seven items was shown, but without any values addressed to its 12 response answers.

They were asked to rank the responses according to their opinion regarding the severity of the symptom; from the response of the highest to the lowest negative impact on QOL.
Ranking the responses of the original score

The Colostomy Impact Score

Do you experience embarrassing smells from your stoma-bag?
- No, never 0
- Yes, less than once a week
- Yes, at least once a week

Do you experience seepage of faeces under the sticking plaster?
- No, never 0
- Yes, less than once a week
- Yes, at least once a week

What is the consistency of your faeces?
- Hard and lumpy
- Formed and soft
- Mushy
- Watery
- Variable

Do you ever experience pain in and around the stoma?
- No, never 0
- Yes

Do you experience any skin problems around your stoma?
- No, never 0
- Yes

Have you noticed a bulge around the stoma?
- No 0
- Yes, I have a small bulge (under 10 cm)
- Yes, I have a larger bulge (over 10 cm)

Who manages your stoma care?
- I do it all myself 0
- I need support and instruction
Statistical analysis

**Good match** when the value is identical or differed by no > one point.

**Moderate match** when the value differed by two points.

**Poor match** when the value differed by more than two points.

Kruskal Wallis H test was used to compare between the responses values between the 5 profession groups.
Results (Task two)

- **Consultants**: 33.33% Good match, 17.31% Moderate match, 50.57% Poor Match
- **Stoma nurses**: 31.57% Good match, 19.44% Moderate match, 50.93% Poor Match
- **Trainees**: 30.75% Good match, 19.54% Moderate match, 50.75% Poor Match
- **Ward nurses**: 49.71% Good match, 26.85% Moderate match, 50.93% Poor Match
- **Medical students**: 33.33% Good match, 16% Moderate match, 50.57% Poor Match

Professions

- Good match
- Moderate match
- Poor Match

Significant difference between professions: P value 0.108

Note: Poor response matching.
Results (part two)
Recruitment was confined to

- The centers with collaborative research work with the dept.
- One stoma nurses association
- One student network.
Conclusion

- The results of this study draw the attention towards the discrepancy in perspectives between colostomy patients and the healthcare providers.

- Further awareness and a better understanding of patients’ perspectives are required; not only would lead to better preoperative counseling but also better post-treatment management and consequently improve patients’ quality of life.
Further reading

Members of the Colostomy Impact Score study group:

- A. D’Hoore (Belgium)
- E. Espin (Spain)
- K. Buzatti (Brazil)
- M. Wong (Singapore)
- N. Smart (UK)
- N. Figueiredo (Portugal)
- P. Nilsson (Sweden)
- R. Madoff (USA)
- S. Wexner (USA)
- T. Cecil (UK)
- T. Oresland (Norway)
- W. Omar (Egypt)
- W. Borstlap (Netherlands)

Patient and healthcare professional perceptions of colostomy-related problems and their impact on quality of life following rectal cancer surgery

H. Elfeky, A. Thyø, D. Nepogodiev, T. D. Pinkney, M. White, S. Laurberg, P. Christensen, the Colostomy Impact Score study group

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Thank You!