Fecal immunochemical test based colorectal cancer screening
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CHAPTER 10

Patients’ perception of colonoscopy: patients with inflammatory bowel disease and irritable bowel syndrome experience the largest burden

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ABSTRACT

Background: Colonoscopy is a frequently performed procedure worldwide with a negative image leading to reluctance in undergoing the procedure. Perceptions could differ depending on the specific indication for the colonoscopy. Aims: to compare patient satisfaction with the colonoscopy procedure between five different patient groups: inflammatory bowel disease (IBD), familiar predisposition for cancer, adenoma/carcinoma surveillance, symptoms suggestive of cancer, and irritable bowel syndrome (IBS).

Methods: Prospective questionnaire study in two regional hospitals and two tertiary teaching hospitals in the Netherlands. 797 consecutive patients scheduled for colonoscopy between October 2009 and June 2010: 280 (35%) symptoms suggestive of cancer, 153 (19%) adenoma or carcinoma surveillance, 146 (18%) IBD, 104 (13%) familial predisposition and 114 (14%) IBS-like symptoms were included. Two questionnaires were administered: one on the day of the procedure; another 6 weeks after the procedure. Main outcome measures were embarrassment, pain, burden, most burdensome aspect, and overall level of satisfaction.

Results: IBD and IBS patients reported significantly more embarrassment and burden from the bowel preparation phase (p=0.040 and p=0.018) and more pain during the colonoscopy procedure (p=0.018). This difference in pain was also seen when adjusting for volume of sedation administered, familiarity with the endoscopist, duration of the colonoscopy or whether or not an intervention was performed. All patient groups were less satisfied with the procedure at six weeks than directly after the colonoscopy; they recalled more embarrassment and burden, but less pain.

Conclusions: Patient groups, defined by indication for colonoscopy, experience the colonoscopy procedure differently.
INTRODUCTION

Colonoscopy is a frequently performed procedure with rising demand, and it is performed both diagnostically and therapeutically for a multitude of indications. Although persons may be considered to benefit from colonoscopy from a health point of view, a significant proportion of them is reluctant to undergo the procedure because of a negative perception or prior negative experiences, by themselves or reported by others.

A study by Bleiker and colleagues has shown that 25% of patients with a family history of colorectal cancer deviate from recommended colonoscopy screening intervals because of perceived barriers such as discomfort and embarrassment[1]. Pena and colleagues showed that pre-procedural nervousness was a strong predictor of unwillingness to undergo a repeat procedure[2]. Lowering the anticipated embarrassment and discomfort and improving patient satisfaction with the procedure therefore seems an important link in improving adherence to recommended colonoscopies.

For the individual, experienced burden is most likely the result of a multitude of factors, which are mutually dependent. Patients scheduled for colonoscopy constitute a large, heterogeneous group that shows variability with respect to gender, age, symptoms, personal and medical history and the number of previous colonoscopies. Crohn’s disease and ulcerative colitis, for instance, are most commonly diagnosed in late adolescence and early adulthood[3]. Colonoscopies performed to rule out cancer or because of adenoma or carcinoma surveillance are more common in persons aged over 50. Furthermore, inflammatory bowel disease patients and patients with a familial predisposition have to undergo multiple colonoscopies at regular intervals. We hypothesized that the indication for which one has to undergo a colonoscopy affects the experience.

The aim of this study was to explore differences in colonoscopy perceptions based on the indication for the procedure. We compared the perception of the colonoscopy at baseline and six weeks after the procedure between patients that had to undergo a colonoscopy because of inflammatory bowel disease, because of adenoma and/or carcinoma surveillance, for a familial predisposition for cancer, for symptoms suggestive of cancer/adenomas, and for symptoms suggestive of irritable bowel syndrome.

METHODS

Study design and questionnaires

The study was designed as a prospective questionnaire study. All consecutive patients scheduled for colonoscopy in two tertiary teaching hospitals and two regional hospitals in the Netherlands were invited to participate. Exclusion criteria were: colonoscopy under propofol, cognitive impairment and inability to understand written Dutch. Patients who had to undergo a colonoscopy for an emergency indication were also excluded.

Consenting participants were asked to complete two questionnaires: a baseline questionnaire directly after the procedure and a follow-up questionnaire 6 weeks thereafter. The baseline questionnaire was completed on the day of the colonoscopy after recovery from sedation. Questionnaires were not administered until just before leaving the hospital, when
persons were able to carry on a normal conversation. All participants who completed the baseline questionnaire were sent a follow-up questionnaire 6 weeks after the colonoscopy procedure by postal mail.

**Patient questionnaires**

Questionnaire items were adapted from earlier studies on the burden of upper gastrointestinal endoscopy and CT colonography and studies among prostate and breast cancer patients[4-9]. These items had been adjusted to fit the colonoscopy setting by a team of endoscopy experts. They were subsequently submitted to a test group of 10 colonoscopy patients to check for clarity. The statements included in the questionnaire section on ‘contributors to satisfaction’ were taken from a previous study by our research group that compared patients’ and endoscopists’ perception of the colonoscopy procedure as assessed by 55 items derived from focus group sessions with colonoscopy patients. A more detailed description of the questionnaire design is reported elsewhere[10]. The 18 items on satisfaction used for the current questionnaire were the ones that had received the highest mean importance scores in the study described above. Gender and date of birth were extracted from the hospital registry.

**Embarrassment, pain and burden**

We evaluated the level of embarrassment (feelings of self-consciousness, shame, or awkwardness), the level of pain (unpleasant physical sensation) and the level of burden (feelings that cause worry, hardship, or distress) associated with several aspects of the procedure: burden of drinking of the bowel preparation, burden/embarrassment/pain of the bowel preparation (i.e. the bowel preparation phase), burden/embarrassment/pain with the introduction of the colonoscope, burden/embarrassment/pain with the colonoscopy procedure itself (‘the moving around of the colonoscope in the patient to reach the cecum’), burden of recovering in the recovery room, and burden of waiting for the result. These were all assessed after the procedure.

Participants were asked to rate all items on 5-point Likert scales, anchored at 1 (“not at all embarrassing/painful/burdensome”) and 5 (“very embarrassing/painful/burdensome). Overall levels of embarrassment, pain and burden were elicited both at baseline and at follow-up.

**Most burdensome part of the procedure**

Patients were invited to indicate the most burdensome part of the procedure. Available options were: bowel preparation phase; colonoscopy itself; recovering from sedation; waiting for the results. The most burdensome aspect of the procedure was elicited at baseline and at follow-up.

**Overall satisfaction**

Overall satisfaction with the procedure was elicited using a 10-point numerical scale (1 not at all satisfied and 10 very satisfied). Overall satisfaction was elicited at baseline and at follow-up.

**Sedation**

Patients were asked to indicate their level of satisfaction with sedation received on a 5-point Likert scale anchored at 1 (“not at all satisfied”) and 5 (“very satisfied”). A second item
elicited the perceived adequacy of sedation. This could be scored on a 3-point scale (too little – adequate – too much).

**Familiarity with the endoscopist performing the procedure**
Patients were asked whether they were familiar with the endoscopist who performed the procedure (yes – no) and to indicate the importance of this item on a 5-point Likert scale anchored at 1 (“not at all important”) and 5 (“very important”).

**Contributors to satisfaction**
Participants were offered 18 statements regarding the colonoscopy preparations and procedure and were asked to pick the three items they felt would contribute most to a higher level of satisfaction.

**Medical history**
Number of prior colonoscopies and history of previous abdominal surgery were elicited with 2 items.

**Demographic and socioeconomic characteristics**
Ethnicity, educational level and marital status were elicited in the baseline questionnaire through 3 items.

**Endoscopist questionnaire**
The endoscopist who performed the procedure was asked to provide the following information directly after the colonoscopy: his/her own level of experience, the indication for which the colonoscopy was performed, number of prior colonoscopies in the same patient, types and doses of medications administered, type of bowel preparation used (polyethylene glycol or sodium phosphate), interventions performed during colonoscopy, net duration of the procedure (from introduction to removal of the colonoscope).

**Colonoscopy procedures**
The type of bowel preparation depended on the hospital where the colonoscopy was performed and the treating physician. This could either be a polyethylene glycol or sodium phosphate solution. All colonoscopy procedures were routinely performed under conscious sedation using midazolam and either fentanyl or alfentanil. Lesions detected during the colonoscopy were preferably treated within the same procedure. After the procedure patients went to the recovery room. Patients were informed about the preliminary colonoscopy results before leaving the hospital. This was after completing the first questionnaire.

**Data analysis**
All patients for whom the indication for performing the colonoscopy was available were included in the analysis. We classified study participants into five patient groups, based on the information entered by the endoscopist: inflammatory bowel disease patients, patients with a familial predisposition for colorectal cancer (e.g. Lynch syndrome and familial colorectal
cancer), patients with symptoms suggestive of cancer (rectal blood loss, change in bowel habits, unexplained weight loss), patients who had a colonoscopy because of surveillance of previous adenomas and/or cancer, and patients with IBS-like symptoms (abdominal pain or cramping, bloated feeling, gas, alternating bouts of constipation and diarrhea, mucus).

Primary outcome measures were: the levels of embarrassment, pain and burden associated with the different stages of the colonoscopy procedure. In addition we calculated the relative frequencies of the most burdensome aspect of the procedure and the average relative importance of several procedural aspects in their contribution to satisfaction. The level of satisfaction with sedation was also assessed. In addition, the effect of the being familiar with the endoscopist performing the procedure was analyzed. We also evaluated changes in satisfaction and overall embarrassment/pain/burden from baseline to follow-up.

We examined whether there were any differences in outcome measures mentioned above between the five patient groups. Likert-scale scores were treated as interval scores and expressed as means. Differences between groups were tested for statistical significance using ANOVA for continuous data and Chi-square test statistics for categorical data. If any statistically significant differences were observed between groups, we performed a second analysis, adjusting for age and gender using ANCOVA. Other variables that were found to be significantly associated with the outcome measures in analysis were considered possible explanatory factors. These were included as covariates in the multivariable model.

Patients who completed both the baseline questionnaire and the follow-up questionnaire were included in the follow-up analysis. We first compared mean differences between baseline and follow-up in overall satisfaction score and overall embarrassment/pain/burden score for all patients taken together, using the paired student t-test. Differences between groups in the magnitude of the difference between follow-up and baseline scores were tested using ANOVA. Data were analysed using the statistical software SPSS 18.0.

**Ethical approval**
According to Dutch guidelines no written informed consent was needed, because the study was carried out as part of a satisfaction survey.

**RESULTS**

**Patients and response rate**
Between October 2009 and June 2010, 1,164 eligible patients (mean age 54 ±15; 43% males) were invited to participate in the study. Of these, 968 (83%) completed the baseline questionnaire. Reasons for non-participation were: logistical (16%), patient refusal (14%), unspecified (70%). Gender and age distributions were comparable between participants and non participants (Table 1).

**Analysis by patient group**
Of the 968 patients that completed the baseline questionnaire, the indication for the colonoscopy was available for 797 (82%): 280 persons (35%) had had a colonoscopy because of symptoms suggestive of cancer (e.g. rectal blood loss, changed bowel habits),
Table 1. Age and gender distribution of participants and non-participants.

<table>
<thead>
<tr>
<th></th>
<th>Participants (n=968)</th>
<th>Non-participants (n=196)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males, n (%)</td>
<td>411/966 (43)</td>
<td>49/101 (49)</td>
<td>0.25</td>
</tr>
<tr>
<td>Mean age (±SD), years</td>
<td>54 ± 15</td>
<td>56 ± 15</td>
<td>0.16</td>
</tr>
</tbody>
</table>

Gender was unknown in 97 persons and date of birth was unknown in 95 persons.

153 (19%) for adenoma or carcinoma surveillance, 146 (18%) for IBD, 104 (13%) because of Lynch or another familial predisposition and 114 (14%) for IBS-like symptoms. Table 2 summarizes the baseline characteristics per patient group.

Embarrassment, pain and burden
Figure 1 shows the mean levels of burden, embarrassment and pain/discomfort associated with several aspects of the colonoscopy procedure per patient group. The perceived levels of pain and burden of the bowel preparation phase, the embarrassment associated with the introduction of the endoscope and the pain and burden associated with the colonoscopy procedure itself differed significantly between patient groups. After adjusting for gender and age, embarrassment and burden scores associated with the bowel preparation phase (p=0.040 and p=0.018) and pain associated with the colonoscopy procedure (p=0.018) remained significantly different between groups.

To look for possible explanatory factors we explored a number of variables. The type of bowel preparation used (polyethylene glycol or sodium phosphate) was not associated with the level of embarrassment or burden associated with the bowel preparation phase (p=0.16, p=0.61 respectively). The reported level of pain during the procedure was correlated with the level of familiarity with the endoscopist performing the procedure, with persons being familiar with the endoscopist reporting less pain (p=0.003). The level of experience of the endoscopist was not significantly associated (p=0.78). The educational level was not associated with the level of perceived pain (p=0.78).

The level of pain was directly associated with a longer duration of the colonoscopy and having an intervention performed during the colonoscopy (e.g. polypectomy) (p=0.015 and p=0.018, respectively). The reported levels of pain associated with the procedure itself were similar for patients with and without analgetics and sedatives (p=0.83 and p=0.34 respectively). The volumes of midazolam and alfentanil administered were positively associated with the reported level of pain (p<0.001 and p=0.03 respectively) whereas there was no association with the volume of fentanyl (p=0.42). Prior abdominal surgery did not result in higher reported levels of pain (p=0.21) nor did having the colonoscopy performed when the patient had an active mucosal inflammation in the colon (p=0.21).

The average level of pain associated with the colonoscopy procedure itself remained significantly different between patient groups after adjusting for differences in the volume of midazolam and alfentanil administered, the familiarity with the endoscopist, the duration of the colonoscopy, and whether or not a procedure was performed (p=0.045).
**Figure 1.** Mean levels of burden, embarrassment and discomfort per procedural aspect by patient group (significance of difference between groups in univariate analysis).

**Most burdensome aspect of the procedure**

Figure 2 displays the distribution of what patients perceived overall as the most burdensome part of the colonoscopy procedure when offered the choice between the phase of the bowel preparation, the colonoscopy procedure itself, the recovery from sedation, and the time spent waiting for the results. This distribution differed significantly between patient groups (p=0.013) (Figure 2). Within all patient groups, the majority of patients indicated that the bowel preparation was the most burdensome aspect of the procedure (55% to 76%). In the IBS group a substantial proportion of patients (40%) identified the colonoscopy itself as the most burdensome part of the procedure.
Relative importance of contributors to satisfaction

Figure 3 displays the frequency with which each of a list of 18 aspects of the procedure was chosen as the most important contributor to a more satisfactory colonoscopy procedure organized by patient group. The distribution of items differed significantly between patient groups (p<0.001). Except for IBD patients, all patient groups selected a “good explanation of the colonoscopy” most frequently as most important contributor (13% to 16%). IBD patients chose “bond of trust between doctor and patient” most frequently as most important contributor to satisfaction (13%).

Satisfaction with sedation

For 779 patients (98%), information on whether or not sedation was given was available from the endoscopist questionnaire (Table 2). The majority of patients had received sedatives and/or analgetics during the colonoscopy; in 59 patients (8%) no medications were administered.

IBS patients were least satisfied with the level of sedation (mean score 3.84), followed by IBD patients (mean score 3.99), symptomatic patients (mean score 4.16), surveillance patients (mean score 4.28) and familial predisposed patients (4.37) (p=0.009). After adjusting for gender and age, these differences remained significantly different (p=0.037).

To look for possible explanatory factors we explored a number of variables. The volumes of midazolam and alfentanil administered were negatively associated with the reported level of satisfaction, with patients having received higher volumes of analgetics reporting less satisfaction (p=0.001 and p<0.001 respectively). Such a pattern was not seen for fentanyl (p=0.68). The duration of the colonoscopy and whether or not a procedure was
Figure 3. Importance of contributors to satisfaction by patient group (%).
performed were not associated with the level of satisfaction with sedation (p=0.24 and p=0.33 respectively). After adjusting for the volumes of midazolam and alfentanil used, the difference in satisfaction with sedation was no longer significant (p=0.23).

### Table 2. Baseline characteristics by patient group, n (%).

<table>
<thead>
<tr>
<th></th>
<th>IBD (n=146)</th>
<th>Surveillance (n=153)</th>
<th>Familial (n=104)</th>
<th>Symptoms (n=280)</th>
<th>IBS (n=114)</th>
<th>( P ) value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.017</td>
</tr>
<tr>
<td>Male</td>
<td>60 (41)</td>
<td>76 (50)</td>
<td>47 (45)</td>
<td>122 (44)</td>
<td>33 (29)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>86 (59)</td>
<td>77 (50)</td>
<td>57 (55)</td>
<td>157 (56)</td>
<td>80 (71)</td>
<td></td>
</tr>
<tr>
<td><strong>Mean age ± SD, years</strong></td>
<td>44 ±15</td>
<td>60 ±12</td>
<td>50 ±12</td>
<td>58 ±12</td>
<td>50 ±15</td>
<td>&lt;0.001¹</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.024</td>
</tr>
<tr>
<td>Low</td>
<td>19 (14)</td>
<td>40 (28)</td>
<td>16 (16)</td>
<td>57 (22)</td>
<td>22 (21)</td>
<td></td>
</tr>
<tr>
<td>Medium</td>
<td>63 (47)</td>
<td>51 (35)</td>
<td>40 (40)</td>
<td>102 (40)</td>
<td>54 (52)</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>53 (39)</td>
<td>53 (37)</td>
<td>44 (44)</td>
<td>95 (37)</td>
<td>27 (26)</td>
<td></td>
</tr>
<tr>
<td><strong>Previous colonoscopies</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>None</td>
<td>32 (22)</td>
<td>11 (7)</td>
<td>45 (43)</td>
<td>197 (71)</td>
<td>70 (62)</td>
<td></td>
</tr>
<tr>
<td>1 to 2</td>
<td>56 (38)</td>
<td>106 (69)</td>
<td>48 (46)</td>
<td>71 (25)</td>
<td>38 (34)</td>
<td></td>
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<tr>
<td>&gt; 2</td>
<td>58 (40)</td>
<td>36 (24)</td>
<td>11 (11)</td>
<td>11 (4)</td>
<td>5 (4)</td>
<td></td>
</tr>
<tr>
<td><strong>Previous abdominal surgery</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>None</td>
<td>48 (34)</td>
<td>64 (44)</td>
<td>21 (22)</td>
<td>75 (28)</td>
<td>44 (42)</td>
<td></td>
</tr>
<tr>
<td><strong>Medication</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.14</td>
</tr>
<tr>
<td>None</td>
<td>10 (7)</td>
<td>15 (10)</td>
<td>11 (11)</td>
<td>20 (7)</td>
<td>3 (3)</td>
<td></td>
</tr>
<tr>
<td>Midazolam</td>
<td>130 (92)</td>
<td>129 (87)</td>
<td>86 (86)</td>
<td>245 (89)</td>
<td>109 (96)</td>
<td></td>
</tr>
<tr>
<td>Fentanyl/alfentanil</td>
<td>96 (68)</td>
<td>99 (66)</td>
<td>72 (72)</td>
<td>176 (64)</td>
<td>53 (47)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>1</td>
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<tr>
<td><strong>Doses of medication</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.003²</td>
</tr>
<tr>
<td>Mean dose midazolam</td>
<td>5.12</td>
<td>4.58</td>
<td>5.09</td>
<td>4.71</td>
<td>4.88</td>
<td></td>
</tr>
<tr>
<td>± SD, mg</td>
<td>±1.64</td>
<td>±1.49</td>
<td>±1.32</td>
<td>±1.11</td>
<td>±1.14</td>
<td></td>
</tr>
<tr>
<td>Mean dose fentanyl</td>
<td>0.07</td>
<td>0.06</td>
<td>0.06</td>
<td>0.06</td>
<td>0.06</td>
<td>0.10</td>
</tr>
<tr>
<td>± SD, mg</td>
<td>±0.04</td>
<td>±0.02</td>
<td>±0.02</td>
<td>±0.02</td>
<td>±0.04</td>
<td></td>
</tr>
<tr>
<td>Mean dose alfentanil</td>
<td>0.58</td>
<td>0.54</td>
<td>0.54</td>
<td>0.52</td>
<td>0.56</td>
<td>0.30</td>
</tr>
<tr>
<td>± SD, mg</td>
<td>±0.19</td>
<td>±0.15</td>
<td>±0.15</td>
<td>±0.11</td>
<td>±0.15</td>
<td></td>
</tr>
</tbody>
</table>

¹ significant differences between all subgroups except surveillance vs symptoms and familial vs IBS.
² significant differences between IBD vs surveillance and IBS vs symptoms.

### Importance of familiarity with the performing endoscopist

Of all patients undergoing a colonoscopy, 281 (35%) patients were not familiar with the endoscopist performing the endoscopy while 498 were (63%). When asked how important they felt being familiar with the person that performs the colonoscopy was, 35% responded “not at all important” and 22% “very important” (mean score 2.72). Mean scores on the importance of being familiar with one’s endoscopist differed significantly between patient groups (\( p=0.001 \)). Being familiar with the endoscopist was felt most important to surveillance...
and IBD patients (mean scores of 2.95 and 2.94 respectively) followed by familial predisposed patients (mean score 2.84), symptomatic patients (mean score 2.67) and lastly IBS patients (2.21). After adjusting for gender, age and the number of previous colonoscopies these scores remained significantly different (p=0.026), with IBD patients still having the highest mean importance score (2.96) but now followed by familially predisposed patients (mean score 2.90) and surveillance patients (mean score 2.77). Symptomatic patients and IBS patients still had the lowest mean importance scores after adjustment.

Change in perception over time
A total of 633 (65%) patients completed both the baseline questionnaire and the follow-up questionnaire. Overall, patients were less satisfied at follow-up after 6 weeks compared to baseline (8.10 to 7.85; p<0.001). The levels of perceived embarrassment and burden increased over time (2.17 to 2.32; p=0.001 and 1.40 to 1.57; p=0.001 respectively) whereas the experienced level of pain decreased (2.32 to 2.09; p<0.001). Figure 4 displays the change in overall satisfaction, embarrassment, burden, and pain for each patient group separately. The size of the difference was similar in all patient groups for each of the four the measures (p=0.18; p=0.24; p=0.98 and p=0.47 respectively).

DISCUSSION
This study assessed patients’ experiences with the colonoscopy procedure. As expected, the perceptions of patients undergoing a colonoscopy differed with the indication. One of the surprising findings of this study was the observation that patients with IBD and IBS in general have worse perceptions of the colonoscopy, also after controlling for potential confounders such as differences in the volumes of sedation and number of previous colonoscopies. On average, these patient groups reported the largest burden from the procedure, as reflected by the highest embarrassment, pain and burden scores and the lowest satisfaction scores, compared to the groups of familially predisposed, surveillance and symptomatic patients. Patient groups also differed significantly in their perception of what specific aspects of the colonoscopy procedure they felt would add most to their satisfaction with the procedure.

In concordance with previous studies the vast majority of patients within all five patient groups considered the bowel preparation phase, and especially the drinking of the laxative, as the most burdensome aspect of the entire procedure[11][12]. In this respect, IBD patients reported significantly more burden from the bowel preparation phase than the other patient groups. IBD patients also felt to a larger extent that a better taste of the laxative would contribute to a more satisfactory procedure. A possible explanation for this different perspective might be that among IBD patients, the largest proportion of patients with more than two previous colonoscopies was seen. Possibly, IBD patients are more familiar with having to go through the preparation phase and therefore experience a larger burden. IBD is a chronic disease requiring regular hospital visits, both scheduled and in case of a flare-up, which could be an explanation for the finding that the items pertaining to continuity of care were assigned higher importance score by this group of patients. For example, whereas the other patient groups felt that an adequate explanation of the
Figure 4a-d. 4a change in overall satisfaction score (range 1-10) from baseline to follow-up; 4b change in overall burden score (range 1-5) from baseline to follow-up; 4c change in overall embarrassment score (range 1-5) from baseline to follow-up; 4d change in overall pain score (range 1-5) from baseline to follow-up.
Colonoscopy procedure was most important in their satisfaction with the procedure, IBD patients indicated that the bond of trust with their treating physician was most important. In this respect, being familiar with the endoscopist who performed the procedure, and having a doctor that knows all about one’s personal history were also more often rated important. These concerns were shared by the group of patients who had to undergo a colonoscopy because of surveillance for adenomas or cancerous lesions, also a group of patients regularly attending the endoscopy department.

This study found that IBS patients also reported a worse overall perception of the colonoscopy, in comparison to other patient groups. This might be explained in part by the fact that the symptoms reported by IBS patients are often similar to those of IBD patients, such as abdominal pain and bloating, altered bowel habits, and fatigue. Several studies have assessed health related quality of life in IBD and IBS patients. Both IBS and IBD patients have been found to have a reduced quality of life, as manifested by poorer sleep, problems with employment, relationships, sexual functioning, leisure, travel and diet[13]. However, on several aspects IBS patients differed from IBD patients: they more often experienced the colonoscopy procedure itself, not the bowel preparation, as most burdensome. In addition, they more often experienced the waiting for the results as most burdensome. This was also seen within the group of symptomatic patients. IBS and symptomatic patients may have in common that they experience symptoms for which they do not have an acceptable explanation, and this insecurity could potentially underlie the greater importance these patients groups attach to the hearing of the results of their colonoscopy.

Strengths of our study are the large and unbiased study sample, invited at different endoscopy centers, allowing our results to be generalized to other colonoscopy patients. This study has a number of potential limitations. We distributed the baseline questionnaire after recovery from sedation, and this could have influenced the perception of the colonoscopy, due to prolonged effects of the sedatives. Since timing was similar for all patient groups this would probably not have affected the differences between patient groups observed in our study but it could have led to a more optimistic initial rating, compared to the rating 6 weeks after the colonoscopy.

Our study design did not allow us to take into account the anticipatory feelings of patients towards the colonoscopy. A previous study found that pre-procedural nervousness was a strong predictor of an adverse endoscopic experience, which could also have played a role in our population[2].

While designing the present study we searched for validated questionnaires for patient experiences with the whole colonoscopy procedure, on a detailed level, and from a patient perspective. Since we did not find any suitable questionnaires we designed a new one, based on previous instruments. We acknowledge that this new instrument – with existing items – had not been validated in its present form. The most widely used questionnaires to assess patient satisfaction with endoscopy procedures are the mGHAA-9 and the Global Rating Scale (GRS)[14]. The mGHAA-9 is a modified version of a more general satisfaction tool (the GHAA-9)[15]. The mGHAA-9 assesses patient satisfaction with 6 aspects of the colonoscopy procedure whereas the GRS is a much more elaborate measure. Previous work
in our centre, using focus group sessions with colonoscopy patients, revealed a substantial number of concerns that were not covered by the mGHAA-9 or the GRS[10]. To be sure that all relevant items would be incorporated in the questionnaire we designed the current questionnaire which since has been used in other studies[16].

This study has shown that different patient groups have different perceptions of the colonoscopy procedure. Future studies should look into these differences in more detail, ideally taking pre-procedure anxiety into account. Since our last measurement was six weeks after the colonoscopy it would be interesting to know if the observed between group differences persist after a longer period of time. It would also be interesting to explore in more detail why scores change over time. Maybe scores were affected by a rapid follow-up appointment in which the findings were explained. In this case, scores from persons with a rapid follow-up appointment can be expected to differ from those who did not have such an appointment. Should this indeed be the case, it is important to provide persons with a follow-up appointment within 6 weeks to increase satisfaction.

Based on the findings described above, patient satisfaction with the colonoscopy procedure - and thereby adherence to future procedures – may be improved by targeted interventions, taking into account differences in expectations and desires between patient groups. In IBD and surveillance patients and other patients regularly frequenting the hospital, for example, efforts should concentrate on safeguarding the continuity of care. This could be done by minimizing changes of doctors and by offering easy access to one’s treating physician. For both IBD and IBS patients, developing and refining measures for adequate pain control during the procedure could help in improving patient satisfaction. For all patient groups, the search for more acceptable bowel preparations should be continued in an effort to lower the burden associated with this phase of the procedure, perceived to be the most burdensome aspect of colonoscopy. Colonoscopy centres could also consider involving patients in decisions surrounding the procedure, by allowing patients to express a preference for endoscopist, for timing of the colonoscopy, for type of bowel preparation and whether or not to receive sedation.
REFERENCES


