Inflammatory bowel disease (IBD) position statement of the Italian Society of Colorectal Surgery (SICCR): general principles of IBD management

G. Pellino¹ · D. S. Keller² · G. M. Sampietro³ · V. Annese⁴ · M. Carvello⁵ · V. Celentano^{6,19} · C. Coco⁷ · F. Colombo³ · N. Cracco⁸ · F. Di Candido⁵ · M. Franceschi⁹ · S. Laureti¹⁰ · G. Mattioli¹¹ · L. Pio¹² · G. Sciaudone¹ · G. Sica¹³ · V. Villanacci¹⁴ · R. Zinicola¹⁵ · S. Leone¹⁶ · S. Danese¹⁷ · A. Spinelli⁵ · G. Delaini¹⁸ · F. Selvaggi¹ on behalf of the Italian Society of Colorectal Surgery (SICCR)

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Abstract

The Italian Society of Colorectal Surgery (SICCR) promoted the project reported here, which consists of a Position Statement of Italian colorectal surgeons to address the surgical aspects of inflammatory bowel disease management. Members of the society were invited to express their opinions on several items proposed by the writing committee, based on evidence available in the literature. The results are presented, focusing on relevant points. The present paper is not an alternative to available guidelines; rather, it offers a snapshot of the attitudes of SICCR surgeons about the general principles of surgical treatment of inflammatory bowel disease. The committee was able to identify some points of major disagreement and suggested strategies to improve quality of available data and acceptance of guidelines.

Keywords Inflammatory bowel disease · Crohn's disease · Ulcerative colitis · Inflammatory bowel diseases · Surgery · Pouch

Introduction

Patients with inflammatory bowel diseases (IBD) need to be treated in specialized centers under the care of multidisciplinary teams. Both Crohn's disease (CD) and ulcerative colitis (UC) require expertise and dedicated facilities. Several international societies have been developing authoritative guidelines to aid the management of IBD [1–12]. In 2015, the Italian Society of Colorectal Surgery (SICCR) conducted a Delphi exercise involving Italian experts, members of the society, concerning the surgical management of IBD [13, 14] and several areas of moderate agreement were identified. This is the third manuscript resulting from the SICCR project repeated in 2019, dealing with the general principles of IBD management. As reported in the first manuscript

from the 2019 SICCR project [13], the current manuscript is not intended to replace the available guidelines; rather, it should stimulate discussion about the surgical issues of IBD among experts at a national level and draw attention to the importance of applying pathways of management in everyday practice nationally. A patient representative was involved in the entire process.

This position statement does not set forth strict rules of conduct, rather it should be interpreted as a decisional aid to be adapted to each individual patient.

Methods

The methods have been thoroughly described in the manuscript in the Position Statement for the surgical treatment of CD [13].

Briefly, a steering committee of experts, including a patient representative (SL), an external advisor (DSK), and an external expert supervisor (SD), identified experts who were invited to participate in the project. Each collaborator contributed with a specific section and drafted the

List of members for The Italian Society of Colorectal Surgery SICCR are given in acknowledgement section.

✉ G. Pellino
gipe1984@gmail.com

Extended author information available on the last page of the article

statements with evidence levels (EL) graded according to “The Oxford Levels of Evidence 2” of Oxford Centre for Evidence-Based Medicine OCEBM (<https://www.cebm.net/index.aspx?o=5653>), along with a brief supporting text. Contributions were circulated via SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA, www.surveymonkey.com). Answers were reviewed by the steering committee, and statements and supporting text that achieved less than 80% of agreement reviewed and submitted for a second round of voting.

Statements that did not achieve 80% were either deleted or moved to the supporting text. Some statements with “> 80% agreement” were revised to include the comments received.

Perioperative phase

Disease assessment

Item 1

Diagnosis of IBD requires a combination of clinical, endoscopic, radiological, and histological investigations (EL 3). None of these, alone, is specific for Crohn’s disease (CD) or ulcerative colitis (UC) (EL3). [Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

Diarrhea for 6 weeks, rectal bleeding, abdominal pain, weight loss and low energy level are the main clinical features common to both the diseases [14]. The most invalidating symptom in UC is urgency in up to 73% of patients [15]. It is important to assess urgency [16]. Colonoscopy with intubation of the terminal ileum is the preferred investigation to study the mucosa, but there is no single specific endoscopic feature for UC and CD. Endoscopic biopsies have less diagnostic accuracy than surgical specimen examination. In fact, even in referral IBD centers, following ileo-anal pouch construction the reclassification of UC into CD occurs in up to 10% of cases [17]. There is not a single histological lesion in UC that is not present in CD, nevertheless the differential diagnosis is the type of infiltration: in UC dense and diffuse, whereas in CD focal and discontinuous inflammation.

Item 2

The clinical assessment of oral, small bowel and anal canal involvement may help to guide the differential diagnosis between CD and UC (EL4). Extraintestinal manifestations and family history should be investigated (EL5).

[Agreement: “Agree” 100%, II round]

The mainstay of differential diagnosis (UC vs CD) is still the holistic and global assessment by the clinician.

The simultaneous presence of different clinical features (severe anal disease with small bowel involvement in CD, severe rectal inflammation with oral pyostomatitis vegetans in UC) may be more reliable than any single histological feature. A positive family history of IBD has been reported in 1.5–28% and 1.5–24% of CD and UC probands, respectively. Several studies have reported high concordance rates for the type of IBD: for CD and UC familial studies have shown concordance rates of 67–89% [18].

Item 3

Oral lesions are more common in CD (EL3). Small bowel involvement is specific to CD; a limited involvement of the terminal ileum only does not exclude the diagnosis of UC (EL3).

The incidence of oral lesions in CD ranges between 20 and 50%. Oral manifestations may occur in 4–10% of patients with UC. Aphthous ulcers are the most common type in IBD patients [19]. Pyostomatitis vegetans is more frequent in UC than in CD [20]. Backwash ileitis is a condition seen in 10–20% of total colectomy specimens of patients with ulcerative colitis. Historically, the involvement of the ileocecal valve has been reported as the cause of backwash ileitis [21]. Recently, a prospective case–control study reported terminal ileitis without involvement of the right colon and cecum in 22% of UC patients. The inflammation was characterized as mild in 94% of the cases and chronic inactive in 6%. It has been suggested that terminal ileitis is a primary extracolonic manifestation not due to backwash [22]. It has been reported that pre-ileal pouch ileitis and pre-stomal ileitis could be an expression of UC rather than CD [23]. In pre-pouch ileitis, the histology shows a continuous infiltrate similar to UC.

Item 4

Perianal disease is more frequent and aggressive in CD, but may be present in up to 10% of UC patients (EL3). Gastroenterologists should be familiar with basic assessment of perianal disease to optimize interdisciplinary approach (EL4).

[Agreement: “Agree” 94.1%, “Disagree” 5.9%, round II]

Perianal disease is common in CD occurring in 30–70% of the patients. Perianal manifestations may occur in up to 10% of the patients with UC. Rectovaginal fistula has been usually considered specific for CD occurring in 10% of women. Rectovaginal fistula has been reported in 2–3% of UC patients. The largest series of rectovaginal fistula in UC suggested a correlation with severity of rectal disease (rectal strictures, deep ulceration, widened presacral space), whereas in patients with CD and recto-vaginal fistula the inflammation may be minimal or mild [24].

Item 5

MR enterography should be used in patients with the suspicion of CD and newly diagnosed CD (EL2).

[Agreement: “Agree” 94.1%, “Disagree” 5.9%, round II]

Magnetic resonance (MR) enterography is the ideal tool to detect the extent of the disease, active small bowel disease, strictures, abscesses and entero-enteric fistulas [25, 26]. Intestinal ultrasound (US) is cost-effective, simple and does not require sedation and exposure to ionizing radiation, but dedicated expertise is required as it is operator dependent [27]. Computed tomography (CT) enterography should be used if MR enterography is not feasible or not tolerated. Small bowel capsule endoscopy can reliably assess mucosal disease, but should be used cautiously if symptoms suggest obstruction or stricturing small bowel CD [28]. The possibility of capsule impaction should be considered, especially in patients with known CD [10, 29]. Small bowel imaging with fluoroscopic barium small bowel follow-through could be used for the initial diagnosis of IBD, as it is a dynamic examination providing information on the distensibility of the small bowel [27]. This may help to differentiate functional from organic stenosis. A prospective study of small bowel follow-through for newly diagnosed IBD reported a sensitivity and specificity of 72% and 100% [30]. Nevertheless, for the initial assessment and exclusion of CD, small bowel capsule endoscopy, intestinal US, MR enterography and CT enterography are superior to small bowel follow-through [31]. Recently, the utility of hybrid positron emission tomography (PET)/MR enterography in assessing the degree of inflammation in CD strictures has been reported, with good pathology correlation [32, 33]; however, the examination is not easily available and is expensive.

Item 6

Social life (work, family, sexual activity, leisure time) should be investigated to assess the actual burden of disease (EL4). Specific quality of life scores should be used.

[Agreement: “Agree” 88.2%, “Partially agree” 5.9%, “Disagree” 5.9%, round II]

IBD significantly affects patients in their daily life and social functioning (work, education and social life) and treatment must be directed towards improvement of patients’ quality of life [34]. Often, the choice to promptly switch toward more aggressive therapy can be made according to worsening of social life functioning rather than of biochemical tests. For example, a patient with normal laboratory tests, but with urgency severely limiting the ability to leave home requires a new therapeutic strategy more than a patient with compromised laboratory results but without any limitations in social life [35]. Several validated disease severity

indexes are available, which provide a useful tool for consistent assessment of overall disease severity in patients with IBD [36]. The Inflammatory Bowel Diseases Questionnaire (IBDQ) is considered the gold standard for use in clinical trials, but it might be impractical in clinical practice [37].

Item 7

Several clinical, endoscopic and histological scores have been proposed for IBD assessment, and should be used to monitor disease evolution (EL3).

[Agreement: “Agree” 94.1%, “Disagree” 5.9%, round II]

Firstly, a score should assess the type and the anatomical extension of the disease. The UC Montreal classification defines macroscopic anatomical extension into three subgroups: E1: rectum; E2: left side; E3: proximal to splenic flexure. The CD Montreal classification addresses the location (ileum, colon, ileocolon, upper gastrointestinal tract) and behavior (neither, stricturing, penetrating) [38]. Small bowel involvement could be “localized” (< 30 cm small bowel–ileocecum) or “extensive” (> 1 m ileum) [38]. The most common endoscopic severity scores in CD are CDEIS, SES-CD and Rutgeerts Score. CDEIS and SES-CD are incompletely validated, but extensively applied in clinical trials. Rutgeerts score is used to assess postoperative recurrence in the neoterminal ileum. It has not undergone formal validation, but is applied in clinical trials [39, 40]. UC endoscopic severity scores are CEIS, UCCIS, Baron Score, Mayo Endoscopic Subscore, Powell–Tuck Index, Sutherland Index and PICASSO Score [41]. A recent Cochrane review reported that while the UCEIS, UCCIS and Mayo Clinic Endoscopic Subscore have undergone extensive validation, none of these instruments have been fully validated [42]. Clinical severity indexes are useful for standardizing disease activity and therapy effectiveness. Every clinical score should be easy and quick to use to be suitable for practical use, especially for diseases involving bowel habitus. Most of the clinical scores (CDAI, Mayo clinic score, True-love–Witts Severity Index, SCCAI, UCDAI), are complex and time consuming.

Multidisciplinary team (MDT) management

Item 8

Patients with IBD should be managed by an MDT, including at least the following expertise: gastroenterologists, colorectal surgeons, nurses, stoma therapists, gastrointestinal and interventional radiologists, pathologists, nutritionists, specializing in IBD; and other specialists—according to their individual needs (EL 4).

[Agreement: “Agree” 100%, round II]

Adapted from Brown et al. [8], the aims of an MDT are to advance patient care, provide multidisciplinary input for the patient's care plan, provide shared experience and expertise, improve patient outcome, deliver the best possible care for the patient and obtain consensus on management for a patient with IBD [43]. The introduction of an IBD nurse led to better quality of care and potentially significant cost savings by reducing hospitalization rates and reallocating physician's time resources [44]. Psychological support should also be made available for IBD patients as part of the MDT [8].

Item 9

Options of IBD treatment should be clearly discussed with patients, who should be actively involved in the treatment decision making (EL4).

[Agreement: "Agree" 94.1%, "Partially agree" 5.9%, round II]

UC and CD both have repeated relapses and recurrences with symptoms affecting patients in different ways. Therefore, it is imperative that the patients are involved in treatment decisions [45]. The different specialists of the MDT must communicate as much as possible to ensure the best management of the different phases of the disease [46].

Perioperative optimization

Item 10

Prednisolone ≥ 20 mg daily for > 6 weeks could be a risk factor for postoperative complications (EL4). Preoperative azathioprine/mercaptopurine does not seem to increase the risk (EL3).

[Agreement: "Agree" 88.2%, "Disagree" 11.8%, round II]

Many retrospective studies indicate that a preoperative dose of > 20 mg of prednisolone for > 6 weeks increases the risk of surgical complications [47, 48]. An increase in infective complications and in short-term postoperative pouch-specific complications has been demonstrated. Therefore, patients should be weaned from steroids before surgery whenever possible, otherwise pouch construction should be delayed. It is important to reduce steroid dosage after surgery taking care to avoid the risk of an Addisonian crisis. Mahadevan and colleagues have shown that preoperative treatment with azathioprine/mercaptopurine, even if very close to surgery, does not increase the risk of postoperative complication [49].

Several studies have tried to define the risk of postoperative complications associated with the use of preoperative infliximab, but the results are quite conflicting [50]. There are no randomized studies, but only observational and retrospective series. A meta-analysis [51] published in 2010 showed an increase in short-term postoperative septic

complications, but subsequent studies [52, 53] failed to demonstrate this correlation. Generally, an interval before surgery of 4–6 weeks from the last dose of infliximab is advised [54] and the standard recommendation is to not perform a single stage restorative proctocolectomy in patients currently on anti-tumor necrosis factor (TNF) treatment [55, 56].

More detailed information in CD and UC specifically is reported in the dedicated manuscripts [13].

Item 11

Enteral nutrition or exclusive enteral nutrition may reduce the risk of septic complications in malnourished and fistulizing CD patients (EL3). There are no sufficient data to define the role of parenteral nutrition in the perioperative phase and it should be used only if enteral nutrition is contraindicated (EL3).

[Agreement: "Agree" 72.2%, "Partially agree" 16.7%, "Neutral" 5.6%, "Disagree" 5.6%, round I]

An extensive review on nutritional support in IBD patients has been recently published [57]. It has been demonstrated that preoperative exclusive enteral nutrition in patients with fistulizing CD is associated with a significantly decreased risk of intra-abdominal septic complications and may result in an accelerated recovery and ability to return to work sooner [58]. Enteral nutrition has not been adequately evaluated in active UC and its efficacy needs to be tested in larger cohorts of patients [59]. Surgical intervention in IBD patients should ideally be delayed for 7–14 days whenever possible if malnutrition is identified. In this time, intensive artificial feeding with enteral nutrition should be initiated [59]. Parenteral nutrition should be considered preoperatively only if metabolic needs are not met by enteral nutrition alone or if disease presentation at the time of surgery impedes the use of enteral nutrition [60].

Item 12

Surgery for IBD has an increased risk of thromboembolic complications. Postoperative venous thromboembolism prophylaxis is advised (EL3)

[Agreement: "Agree" 72.2%, "Partially agree" 22.2%, "Neutral" 5.6%, round I]

Compared with the general population, patients with IBD have been shown to have a two- to threefold increased risk of venous thromboembolism [61, 62]. The risk of venous thromboembolism in IBD patients is further increased two-fold following surgery or admission to the hospital with a CD or UC flare; the latter accounts for over 30% of venous thromboembolism in all IBD patients [63, 64]. Patients hospitalized with active IBD should receive thromboprophylaxis at admission [1, 65]. In a recent study by Brady et al. [66], 7078 patients undergoing surgery for CD or UC were evaluated. Postdischarge thromboembolism was more common in patients with UC than with CD (5.8% vs 2.3%;

$p < 0.001$). There are sufficient data indicating that continuing postoperative venous thromboembolism prophylaxis for 4 weeks reduces occurrence of venous thromboembolism complications in patients undergoing laparoscopic colectomy for colon and rectal cancer [67]. Similar recommendations should be applied to patients with IBD to reduce postoperative venous thromboembolism.

Assessment of outcome

Item 13

Assessment of outcome of therapeutic interventions for IBD patients is necessary and strongly recommended (EL4), but the ideal outcome measures have not yet been established univocally.

[Agreement: “Agree” 88.2%, “Partially agree 5.9%, “Disagree” 5.9%, round II]

In recent years, the importance of patient-reported outcome measures has been increasingly recognized [68, 69]. There is large consensus that IBD patients should be assessed on a regular basis [11, 70], but there is little agreement as to which measures in particular should be used. In neoplastic disease, a natural outcome to assess would be survival and disease-free survival, given the major impact on these parameters. In IBD on the other hand, where there is a smaller impact on survival [71], a more tailored outcome measurement must take into account symptoms, function and quality of life. It has been demonstrated that when physicians are compelled to report on patient outcomes, there is a marked improvement in the results of their care [72, 73].

One expert consensus (STRIDE) has tried to define not only which outcomes to monitor, but the target values that should be used to guide clinical practice in both CD and UC (treat to target approach) [74]. These target values would be a combination of clinical and endoscopic parameters, with biochemical parameters used as an adjunct. As biochemical parameters have gained importance (and high-quality evidence) in the last few years, these recommendations have been criticized and considered to be already obsolete [75].

Item 14

Standardized outcome assessment, through the use of a core outcome set in clinical practice may represent a new advancement in IBD treatment. The use of the International Consortium for Health Outcomes Measurement (ICHOM) Standard Set for IBD is encouraged (EL5).

[Agreement: “Agree” 83.3%, “Partially agree 5.6%, “Disagree” 11.1%, round I]

Outcomes measured so far differ both in quality (biochemical, endoscopic, clinical, patient reported) and in

measurement method [e.g., IBDQ and for quality of life (QoL)]. This has resulted in a great heterogeneity in outcome measures in the literature, which in turn translates into considerable difficulty when comparing and analyzing clinical trials [77–78]. All current treatment options, including those recommended in this guideline, have been tested against a number of different outcomes. A core outcome set (COS) is a consensus-derived minimum set of outcomes that should be measured and reported in all clinical trials of a given disease [79, 80]. In many diseases, COS, with which physicians evaluate and report the quality of their care, has been developed and implemented with success [80]. In the USA a collaborative has pioneered this methodology on a small scale and reported a significant increase in remission rates in pediatric CD patients when pre-defined outcomes were reported across the collaboration [73]. For these reasons, it is reasonable to introduce outcome assessment through a COS in IBD, to standardize clinical trials as well as to improve the quality of clinical practice. To date, only one COS has been proposed for IBD care [81], while others are in development. Kim et al. [81] (a team of gastroenterologists, surgeons, specialist nurses, PROM methodology specialists and patients) have produced a consensus identifying four domains which reflected the whole cycle of care for CD and UC: survival and disease control; symptoms, function, and quality of life; disutility of care; and healthcare utilization. Within these domains several outcome measures were chosen to produce the final core set. These include in the short term: overall survival (and cause of death), complication rate, length of hospital stay and quality of life through the IBD control questionnaire. Long-term outcome measures to be added to the previous four include: body mass index (BMI), steroid use, anemia, disease activity through the Manitoba IBD Index (a single-item, patient-defined disease activity measure) [82], diagnosis of colorectal cancer (CRC) and fistula symptoms in CD patients. These should be reported yearly (QoL, Manitoba, anemia every 6 months). A further set of case-mix variables for risk adjustment should be reported only at baseline. No data yet exist to indicate that standardized outcome assessment impacts results of IBD treatment, as these methods have not yet been widely implemented. Nonetheless, results from other specialties are encouraging [72].

The ICHOM standard set does not include many parameters that have been used in various studies in IBD [81]. One outcome that is not present in the ICHOM set is reoperation for disease recurrence. This item is a main factor in assessing and comparing the results of surgical procedures as well as new treatments. Also, various studies have shown that surgery for recurrence carries a substantially higher burden of complications, which become proportionally more frequent with increased number of procedures [83, 84]. Moreover, it is a major source of preoccupation and anxiety for most

patients with CD. Therefore, the use of reoperation data for outcome assessment is advised.

Neoplasia in IBD

Small bowel cancer

Item 15

CD patients have an approximatively 20-fold increased risk of small bowel adenocarcinoma in Crohn's disease (EL1), which is the most frequent small bowel neoplasia for these patients (EL 3). It usually arises in inflamed areas (EL 5) or segments with long-lasting strictures (EL4).

[Agreement: "Agree" 94.4%, "Disagree" 5.6%, round I]

The frequency of small bowel adenocarcinoma is low being approximatively about 2% of all cancer of the gastrointestinal tract; however, it is significantly increased in CD [9, 85]. In a recent meta-analysis of 20 clinical studies including over 40,000 CD patients, the incidence was 0.3/1000 person years duration (CI, 0.1–0.5), which compared to the age-matched background population represents an increase of 18.75 [86]. Interestingly, the same study also reported a significant frequency of cancers arising from CD-associated fistulae (0.2/1000 person years duration [CI 0.0–0.4]). Possible identified risk factors for small bowel adenocarcinoma include distal jejunal/ileal CD localization, strictures and chronic penetrating disease, long disease duration, young age at diagnosis, male sex, use of steroids and immunomodulators and small bowel bypass loops [85]. The tumors developed more often in more inflamed areas, and the use of 5-aminosalicylic acid (ASA) for more than 2 years seemed to reduce the risk (OR=0.16, $p=0.02$) [87]. In the large cohort of an Italian Consortium, the overall survival was worse in CD patients with small bowel adenocarcinoma than in celiac disease patients with these tumors [88].

Cancer associated with fistula in ano

Item 16

Cancer arising on complex perianal Crohn's fistula tracts, mainly mucinous adenocarcinoma, is rare (EL 1).

Substantial risk factors for malignant degeneration are represented by long-standing chronic fistulas (longer than 10 years since onset) and anal stenosis, especially in female patients (EL 2).

[Agreement: "Agree" 100%, round I]

Item 17

In patients with long-standing perianal CD, a change in symptoms, and particularly an unexplained pain, should always raise the suspicion of cancer (EL 2).

Fistula-related cancer presents with non-specific signs and symptoms and is usually at an advanced stage at the time of diagnosis (EL 3).

The gold standard treatment of fistula-associated anal adenocarcinoma in patients with CD is abdominoperineal resection with or without neoadjuvant chemoradiation, but results in terms of survival are poor (EL 4).

[Agreement: "Agree" 100%, round I]

Item 18

Regular and careful surveillance for anorectal carcinoma should be recommended for all patients with perianal CD by means of clinical examination (EL5). Frequency and modalities of surveillance are not defined (EL5). Contrast-enhanced MRI should be performed together with clinical examination in all patients with long-standing active perianal disease (EL5). Screening for anal human papilloma virus (HPV) could also be considered (EL5). EAU with biopsy or fistulectomy (excision of fistula tracts) should be recommended in the case of change or worsening in clinical symptoms that is resistant to medical treatment and/or in the presence of any suspicious lesion (EL 5).

[Agreement: "Agree" 94.1%, "Neutral" 5.9%, round II]

Cancer associated with perianal fistulas in CD is rare [85, 89]. In a meta-analysis with 40,547 patients, the incidence of fistula-related cancer was 0.2/1000 patient/year [86]. Only four patients had fistula-associated adenocarcinomas in a 17-year follow-up study among 6058 patients with perianal fistulas [90]. Occurrence is being increasingly reported [91], and among the total 113 cases described, 52 occurred after 2008 [92]. Mucinous adenocarcinomas are more frequent [93]. Pathogenesis could be associated with local chronic inflammation [94], adenomatous transformation of the epithelium with progression dysplasia–carcinoma or epithelial-to-mesenchymal transition within a longstanding fistula [89]; HPV infection [95, 96]; drug-induced immunosuppression [97]; hypoxia [98]. Immunomodulation could play a key role in the progression from chronic inflammation left in situ to carcinoma [99]. Long-standing perianal CD (> 10 years) is considered to be the main risk factor together with anal stenosis. Symptoms and signs are non-specific, and clinical examination is usually limited by pain, stricture, and/or induration of perineal tissues [100]. Typically, patients present worsening of symptoms, such as increased discharge and/or pain, in spite of medical or surgical treatment [101]. All these factors complicate and delay diagnosis, worsening the prognosis at diagnosis for advanced stage cancer [85, 102, 103]. The gold standard treatment is abdominoperineal

resection with/without neoadjuvant chemoradiation vs. radiation or chemoradiation alone. A rate of local recurrence of 30% after abdominoperineal excision versus 40% after radiation therapy is reported with survival rates of 62% and 60%, respectively [104]. Complete response after neoadjuvant chemoradiation therapy followed by abdominoperineal excision is described [105].

Optimal frequency and modalities of surveillance to detect premalignant lesions and early anorectal cancers are not well defined. Ogawa et al. suggested that patients should undergo surveillance after 7 years of perianal disease [106]. Regular surveillance should be requested for all patients with perianal CD using perianal clinical examination, including digital rectal examination. EUA with biopsy should be recommended in case of any change or worsening in clinical symptoms resistant to medical treatment and/or in the presence of any suspicious lesion [9, 93].

Colorectal cancer

Item 19

There is at least a twofold increased risk of CRC in UC and Crohn's colitis compared with the general population. Risk (mainly for UC) is associated with disease duration (EL 2), disease extent (EL 2), and inflammatory activity (EL 2) and is further increased in case of family history for colon cancer (EL 3) or concomitant primary sclerosing cholangitis.

[Agreement: "Agree" 94.4%, "Disagree" 5.6%, round I]

Item 20

Screening colonoscopy should start 8 years following the onset of symptoms with the aim of ruling out dysplasia (EL 5) or early detection of colon cancer which leads to an improved prognosis and survival (EL 3). The timing of endoscopic surveillance is not clearly defined and should be better tailored on the basis of underlying risk factors (EL5).

[Agreement: "Agree" 83.3%, "Neutral" 5.6%, "Disagree" 11.1%, round I]

The risk of CRC seems to be reduced over time, following the previous alarming meta-analysis of Eaden et al. in 2001, and this is probably due to a better control of disease activity and the activation of program of screening and surveillance [107]. However, two recent meta-analyses of population-based cohorts [108, 109] have estimated an excess standardized incidence ratio (SIR) of 2.4, with increased risk for young age at diagnosis (SIR = 8.6), and extensive colitis (SIR = 4.8). Other important risk factors are a family history of CRC and primary sclerosing cholangitis, particularly in UC. The CRC cancer risk is at

1.9 for CD. Of note, IBD patients tend to develop CRC at younger ages than non-IBD patients and with a more aggressive course.

Surveillance colonoscopy programs reduce morbidity and mortality due to CRC by detecting cancer at an earlier stage with better prognosis or by detecting and resecting dysplasia, reducing CRC incidence [9]. The benefit estimated in years of life saved may be much greater in colitis patients than for general population screening, because IBD-CRC tends to occur earlier in life and modeling studies have shown that life saved per case screened ranges from 1.2 to 5 years in UC patients, compared to 1.2–4 months in general population screening [9, 110, 111]. Disease duration is a major risk factor for the development of IBD-CRC, hence, screening colonoscopy should be recommended when the risk starts to increase (i.e., 8–10 years after the onset of disease). This colonoscopy assesses the extent of disease. The timing of dysplasia progression is not known in IBD. Therefore, intervals between repeat surveillance colonoscopy should be prospectively adjusted to each patient taking into consideration CRC risk factors and previous endoscopic findings [2, 9].

Pouch-related adenocarcinoma is extremely rare, the risk being much lower than in the general population [112, 113].

Dysplasia in IBD

Item 21

Dysplasia and CRC in IBD are strictly related to the duration and extension of the disease, grade of inflammation, young age, and family history of CRC (EL4). The presence of primary sclerosing cholangitis increases the risk of colorectal cancer in ulcerative colitis.

[Agreement: "Agree" 94.1%, "Partially agree" 5.9%, round II]

The risk of developing dysplasia and CRC in the context of IBD increases in relation to several factors, including duration and extension of the disease, microscopic intensity of inflammation, young age of onset and family history of CRC, especially if there is a first degree relative diagnosed with CRC before the age of 50 years [115–116]. Small bowel involvement is a specific risk factor for CD, while the presence of primary sclerosing cholangitis increases the risk of CRC only in UC [115–116].

Item 22

TP53 mutation is the key factor in IBD-associated carcinogenesis. CRC related to IBD may also follow the serrated pathway versus neoplasia, associated with alteration of deoxyribonucleic acid (DNA) repair mechanisms (EL2).

[Agreement: "Agree" 94.1%, "Neutral" 5.9%, round II]

In CRC associated with IBD, mutations are similar to those of sporadic forms, but differ in order and frequency: the functional loss of APC occurs less frequently and usually in later stages, while TP53 is the key factor in IBD-associated carcinogenesis [118–121].

As in sporadic forms, CRC related to IBD may also follow the serrated pathway versus neoplasia, i.e., a hyperplastic polyp, sessile serrated polyp without dysplasia and traditional adenoma. These tumors are associated with alteration of DNA repair mechanisms that induce microsatellite instability and are related to BRAF mutation [118–121].

Item 23

Dysplasia is distinguished endoscopically as visible and invisible. The visible lesions are subdivided into polypoid, if the lesion protrudes in the lumen for more than 2.5 mm, and not polypoid, when the lesion is not protruding or protruding into the lumen for less than 2.5 mm (EL2).

[Agreement: “Agree” 100%, round II]

Item 24

Dysplasia is divided into four categories: negative for neoplasia, low-grade, high-grade, undefined for dysplasia. The presence of inflammation and regenerative/reparative changes of the epithelium make it difficult to identify true atypia: the second opinion of an IBD expert pathologist is recommended (EL3).

[Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

From an endoscopic point of view, dysplasia is distinguished as visible and invisible, defined as dysplasia identified on random biopsies performed on apparently healthy mucosa [122, 123]. The visible lesions are further subdivided into polypoid, if the lesion protrudes in the lumen for more than 2.5 mm, and not polypoid, when the lesion is not protruding or protruding in the lumen for less than 2.5 mm. The lesions can also have distinct or indistinct edges and can be ulcerated [122, 123].

Four categories of dysplasia can be identified at pathology: negative for neoplasia, low-grade non-invasive neoplasia, high-grade non-invasive neoplasia and undefined neoplasia/dysplasia [124, 125].

In the context of IBD, the presence of inflammation and regenerative and reparative changes of the epithelium make it difficult to identify true atypia. In these situations, the “undefined neoplasm” diagnostic category is used, but the second opinion of an IBD expert pathologist is recommended [124, 125].

Item 25

Visible polypoid or non-polypoid lesions can be resected with endoscopic excision when the margins are endoscopically recognizable and the biopsies of

the adjacent mucosa do not show dysplasia. In the case of invisible high-grade lesions, colectomy is recommended (EL2).

[Agreement: “Agree” 94.1%, “Neutral” 5.9%, round II]

The lesions are divided into resectable and unresectable: when the margins are endoscopically recognizable and the biopsies of the adjacent mucosa do not show dysplasia, the lesion is defined resectable. When a resectable visible lesion of the polypoid or non-polypoid type is detected, endoscopic excision may be performed. If the margins of the lesion are barely recognizable, the lesion is considered unresectable and the therapeutic option should be colectomy [123, 126].

For endoscopically invisible lesions, it is recommended to contact experienced IBD endoscopists to assess the possible presence of well-defined, and therefore resectable, lesions and possible synchronous lesions. If an invisible lesion has indefinite margins, the therapeutic choice depends on the degree of dysplasia [123, 126]. In the case of invisible high-grade lesions, colectomy is recommended, although it is possible to perform an endoscopic resection in the absence of outbreaks of dysplasia in the surrounding mucosa, followed however by close endoscopic surveillance [123, 126]. The natural history of low-grade invisible lesions is unclear and therapeutic strategies differ among centers [123, 126].

Intestinal failure in IBD

Risk factors and assessment in IBD

Item 26

The risk factors for intestinal failure in IBD are surgery, especially in case of repeated or extended resection (EL3), and aggressive bowel disease, which is related to disease behavior and young age (EL4).

[Agreement: “Agree” 88.2%, “Partially agree” 11.8%, round II]

Item 27

The assessment of intestinal failure requires specialist multidisciplinary management and is mainly based on serial body weight/BMI measurements, self-screening strategies and laboratory studies (EL3). The role of new biomarkers should be clarified.

[Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

Intestinal failure (IF) is defined by the ESPEN group [127] as “the reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth”; it is possible to functionally differentiate between acute intestinal failure

(short-term and prolonged acute) and chronic intestinal failure (CIF). CD is one of the most common underlying conditions, especially in CIF (22.4%), and short bowel syndrome (SBS) is the most frequent pathophysiological mechanism due to surgery or aggressive disease [128]. Thus, IF risk factors could be related to surgery, such as repeated or extended resection (especially where remaining small intestine is < 200 cm) [129], ostomy creation [129], and perioperative complications [130] or related to disease, such as behavior (penetrating or stricturing) [129, 130] and young age at diagnosis or at surgery [130].

Further studies are required to clarify the role of smoking, a family history of IBD and the effect of medical therapy [131]. Bowel-sparing surgery plays a key role in preventing SBS [132].

The assessment of IF should begin with an attentive appraisal of the patient's nutritional status and its optimization, and this is paramount in surgical patients because it is strongly related to the patient's outcome [46, 133, 134]. The assessment of nutritional status requires multidisciplinary management with the active participation of the dietitian [135] and involves several factors such as serial body weight/BMI measurements, self-screening strategies [Malnutrition Universal Self-Screening Tool (MUST)] [136] and laboratory studies (albumin, iron and micronutrient levels) [139], although these tests can be influenced by the CD-related systemic inflammatory response. In this setting, further studies are required to establish the validity of biomarkers of IF, such as serum citrulline [137] and intestinal fatty acid binding protein [138].

Item 28

IF is an uncommon condition (50 per million people with CIF) that may result from obstruction, dysmotility, surgical resections, congenital defects or disease-associated loss of absorption and characterized by the inability to maintain protein–energy, fluid, electrolyte or micronutrient balance (EL2).

In CD, extensive surgical resections, surgery for complications (EL3) and aggressive small bowel disease (EL4) are the most common causes of SBS and are thus risk factors for IF.

[Agreement: “Agree” 100%, round II]

IF is a debilitating condition characterized by inability to maintain a state of adequate nutrition and/or fluid and electrolyte balance, because of an anatomical and/or physiological disorder of the intestine and can be caused by five major pathophysiological conditions such as extensive resections, intestinal fistula, intestinal dysmotility, mechanical obstruction, congenital defects and extensive small bowel mucosal disease. CD is among the leading causes of intestinal failure, second only to cancer patients (11–17% vs 29–41%) [139, 140]. Three categories exist [141]: type 1 generally occurs

postoperatively and is self-limiting, such as patients developing ileus, requiring short-term parenteral nutritional (PN) support for days or weeks. Type 2 most commonly develops in individuals with abdominal or generalized sepsis following major complicated intestinal resection. Patients require PN for many weeks or months. Type 3 is irreversible, and long-term home parenteral nutrition (HPN) is required. CD is most commonly associated with type 3, but the overall incidence is low. The prevalence of type 3 IF as a percentage of all causes is estimated to be 3% in UC and 29% in CD [142]. UC is rarely associated with type 3 IF because the small intestine is uninvolved, but IF can still occur after perioperative complications. When IF occurs in patients with CD, it is usually due to complications of surgery for intra-abdominal sepsis, extensive primary small bowel disease impairing nutrient absorption, or extensive resection leading to SBS. The first one is the principal cause of IF in CD [127]. Predisposing factors to type 3 IF include: younger age at diagnosis and at first operation, stricturing disease or family history of inflammatory bowel disease [143]. Anatomical classification of SBS is also important, with three different groups [144]:

- Group I: with an end jejunostomy, chronic IF is generally observed if < 1 m of small bowel remains.
- Group II: with jejunocolonic anastomosis, chronic IF is generally observed if < 0.5 m of the small bowel remains with all the colon in place.
- Group III: with jejunio-ileo anastomosis and preservation of the ileocecal junction; this is the “best case” for which only 30–50 cm of small bowel remaining is enough to avoid (chronic) IF.

Principles for the management of IF in IBD

Item 29

Preoperative optimization of the patients, reduction of postoperative complications and bowel-sparing techniques, such as strictureplasty and minimal small bowel resections, all lead to a decreased risk of short bowel syndrome, thus decreasing the risk of intestinal failure (EL2).

[Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

Item 30

Management of IF requires a multimodal approach, not only in the short term but also in the long term, including support for home-based treatment (EL3). In type IIIF, sepsis must be investigated and treated, nutritional support must be provided, a minimum length of small bowel must be preserved and a long-term plan discussed in a multidisciplinary team (EL4).

[Agreement: “Agree” 100%, round II]

Item 31

Home parenteral nutrition should continue to be the primary therapeutic option for IF due to better or comparable long-term survival compared with intestinal transplantation (EL5). Although patient survival rates after intestinal transplantation continue to improve, the risk of developing major complications is still relevant, thus suggesting that intestinal transplantation has a role as a potential life-saving intervention, particularly in patients with difficult venous access or abnormal liver function (EL5).

[Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

Adapted from Vaizey et al. [144]. Surgical management of patients with IF requires expertise in terms of technical challenges and decision-making. Adequate surgical strategies must be used to avoid IF in CD patients. Patients with CD are at 5–10% risk of developing SBS due to repetitive surgical procedures, surgery for complications, wrong pre-operative diagnosis and penetrating small bowel disease. The major risk factor for developing chronic IF in patients with CD is the severity of the small bowel disease, rather than surgical procedures. To reduce surgical complications and avoid this chronic condition, preoperative optimization of the patients, good nutritional status, minimally invasive surgery, and bowel-sparing techniques (strictureplasty or minimal small bowel resections) are recommended [145].

IBD in adolescents and transition. IBD in the elderly

Critical issues in early-onset IBD

Item 32

CD surgery must be limited to a localized intestinal segment in case of small bowel or colonic symptomatic disease not responsive to medical treatment in pediatric patients (EL2). Strictureplasty should be strongly considered as the first step of surgical management even in case of extended intestinal CD (EL4). [Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

In case of a localized intestinal disease, a limited resection must be preferred to reduce the risk of short bowel syndrome in long-term follow-up [146, 147]. There are few studies in literature on strictureplasty for CD in pediatric patients [148]. Compared to intestinal resection, strictureplasty allows intestinal length with the same relapse rate [152]; however, few data are available concerning the outcome of strictureplasties in children. An in-depth discussion

of the topic was beyond the scope of this manuscript. The reader is advised to consult specialized reviews for further information.

Item 33

CD complex perianal fistulae in pediatric patients should be treated with noncutting seton placement as first-line treatment (EL2). Fistulectomy combined with medical treatment can be considered an alternative to stoma diversion in case of complex perianal treatment refractory to medical therapy and seton placement. (EL4).

[Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

The ECCO/ESPGHAN guidelines [147, 149] reported that combined medical therapy with seton placement was the gold standard treatment for complex perianal fistulae.

A NASPGHAN study on perianal fistulae management reports an increased risk of sphincteric lesion following cutting seton placement [150]. The choice of stoma diversion or fistulotomy is a controversial argument in cases of perianal complex fistulae refractory to medical therapy and seton placement. In CD the restoration rate of intestinal continuity after a stoma diversion is relatively low [151]. There is a lack of comparative studies between stoma diversion and fistulectomy. A novel technique associating endorectal pull-through and fistulectomy [152] allows reduction of the stoma diversion rate, with a low incidence of complications.

Item 34

CD laparoscopic resection should be considered an ideal approach in case of localized intestinal disease in pediatric patients (EL1).

[Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

Minimally invasive surgery for pediatric CD is under debate. Several case series and case-control studies showed many advantages in terms of pain management and reduced length of hospital stay [153, 154]. Despite these results, to date there is a lack of strong studies comparing laparoscopic versus open techniques in the pediatric population.

Item 35

UC elective colectomy should be performed in case of active ulcerative colitis and growth retardation despite maximal medical therapy in pediatric patients (EL2). Ileal J-pouch–anal anastomosis should be offered to restore intestinal continuity (EL2).

[Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

In case of steroid-dependent patients with active disease while on infliximab and immunomodulatory treatments, elective colectomy should be performed to allow clinical

control of the patient [155]. Historical patient exposure to anti-TNFs with absence of endoscopic mucosal healing and absence of response after biological treatment at induction are both predictive factors of colectomy. Ileal j-pouch–anal anastomosis despite the risk of postoperative pouchitis has proven to be superior to straight ileo-anal pull-through in terms of fecal continence, stool frequency and perianal sepsis [156]. Two-stage surgical management (colectomy then proctectomy with ileal J-pouch–anal anastomosis) should be preferred to a one-stage procedure because of the lower complication rate; three-stage surgical management should be preferred in case of patients with malnutrition and worse clinical conditions [4, 157, 158]. Colectomy is as effective as immunosuppressants for allowing “catch-up” in growth status in children with growth retardation [159].

Item 36

UC minimally invasive surgery should be considered the gold standard for colectomy and ileal J-pouch–anal anastomosis (EL2).

[Agreement: “Agree” 94.1%, “Partially agree” 5.9%, round II]

Over the years, laparoscopic colectomy and ileal j-pouch–anal anastomosis have been reported as safe and feasible procedures in children [160], with better outcomes in terms of complication rate when compared to the open approaches [161].

Transition of care

Item 37

Patient should be prepared at least 1 year before the transition (EL4). The transition process should be coordinated by a specialist pediatric nurse (EL4).

[Agreement: “Agree” 88.9%, “Neutral” 11.1%, round I]

Item 38

Patients with IBD should actively participate in the transition of care process (EL4). Self-assessment scale can evaluate patient progression during transition (EL4).

[Agreement: “Agree” 100%, round II]

An adequate preparation is needed before the transition with a minimum advance of 12 months to favor the patient’s independent behavior and knowledge of the disease [162]. A transition coordinator, usually a specialist IBD nurse, can help to overcome the gap between pediatric and adult teams [163, 164].

Patients who are actively involved in a transitional program have better outcome in terms of attendance at clinics, drug compliance and hospital admission rate than those who are not involved, optimizing health-care resources

[165]. Self-management analysis (also called self-efficacy) is a behavior tool to improve quality of life that was just reported in pediatric chronic diseases as type 1 diabetes mellitus [166]. A multiple items disease-specific scale has been reported to assess the patient’s progression during transition, to monitor self-management and patient knowledge [167, 168].

IBD in the elderly

Item 39

Elderly IBD patients can be divided into two groups: individuals diagnosed at a younger age who attain an elderly age and those first diagnosed at or after age 60 years. New IBD diagnosis in elderly takes longer and misdiagnosis is quite common (EL3).

[Agreement: “Agree” 94.12%, “Neutral” 5.9%, round II]

The proportion of patients with elderly onset IBD varies from 3 to 21% for CD and 7 to 29% for UC [169]. Elderly patients with long-standing IBD who were diagnosed in younger adulthood may be clinically distinct from those with elderly onset IBD [170].

Compared to younger adults, the initial diagnosis of IBD in the elderly is generally more difficult and consequently takes longer. The differential diagnosis of IBD in the elderly includes infectious colitis, ischemic bowel disease, segmental diverticulitis, NSAID enteropathy, malignancy, microscopic colitis, radiation enteritis and solitary rectal ulcer syndrome. Moreover, the presentation of IBD can be more subtle in seniors. On average, there is a delay in diagnosis of up to 6 years in the elderly compared to 2 years in younger adults [171, 172].

A family history of IBD and the prevalence of extraintestinal manifestations are less common in elderly onset IBD patients [173].

Age-related changes in immune function and the gut microbiome may increase susceptibility to infections, making chronic immunosuppressive therapy in the elderly population less than ideal [174]. In addition, treatments that require frequent laboratory monitoring or regular trips to infusion centers may be more challenging for older patients due to logistical considerations [174, 175].

Item 40

Elderly CD patients appear to have higher rates of isolated colonic disease and disease behavior with less penetrating complications or perianal disease. Patients with older-onset UC have more frequent left-sided disease compared to younger IBD cohorts (EL3).

[Agreement: “Agree” 100%, round I]

Late-onset IBD differs from early onset in many aspects, including location and phenotype of the disease at diagnosis, symptoms at presentation and natural disease progression [174]. Elderly CD patients typically present with colonic involvement (L2 in the Montreal classification) and inflammatory disease behavior (B1), with less frequency of fistula or stricture development compared to younger patients [176]. Further, disease behavior or phenotype in CD does not typically change among the elderly. Elderly UC patients experience more commonly left-sided colitis, while extensive disease and isolated proctitis are proportionally less frequent than in adults [176, 177].

The clinical presentation of UC may be subtle, with less reports of bleeding, diarrhea, or pain, but often the first flare is more severe [176]. Usually, those who remain surgery free after the first flare of disease are more likely to have a more benign disease prognosis in the long term [178].

Item 41

Treatment of IBD in the elderly is complicated by the presence of comorbidities and by the risk of drug interactions, which is exacerbated by polypharmacy. UC elderly onset patients seem to be more likely to undergo surgery, whereas the overall surgery rates between young and elderly patients with CD diagnosed early are similar (EL3).

[Agreement: “Agree” 100%, round I]

Comorbid health conditions such as heart disease, diabetes, cancer, psychiatric disorders and arthritis are commonly present in elderly patients with IBD [170, 171, 179]. Polypharmacy has the potential to increase the risk of drug interactions, and drugs used in the treatment of IBD may contribute to either triggering or worsening concomitant diseases [171].

The choice of the most appropriate therapeutic approach in older patients should be driven by balancing potential benefits and risks on an individual basis. Treatment goals in older IBD patients may focus on immediate symptom relief and improvement of physical functioning to maintain independence, very different from the goals of younger cohorts who may prioritize prevention of long-term disease-related complications [174].

The rates of surgical interventions appear to be higher in older-onset than younger-onset UC at years 1 and 5 after diagnosis, but similar in older-onset CD compared with younger-onset disease [171]. It is unclear whether higher rates of surgery are driven by a less benign natural disease course in older-onset disease, reluctance of physicians to employ immunomodulators, aggressive treatment regimen in elderly patients or complications due to comorbid conditions [174, 175].

In general, elderly patients with IBD are at substantially higher risk of postoperative complications (especially

infections and venous thromboembolism) and mortality, particularly in an emergency setting [170, 177, 180, 181].

The risk of CRC in IBD increases with increasing disease duration, positive family history of IBD, primary sclerosing cholangitis and prolonged and persistent mucosal inflammation [173]. Elderly onset IBD itself is not associated with an additional increased risk of colorectal cancer. CRC screening in the elderly should be balanced with disease severity, comorbidities and life expectancy [177].

A large French cross-sectional study of IBD patients suggests that older age (> 60 years) is not associated with worse quality of life, fatigue or disability [182].

Patient-reported outcome measures in IBD

PROMs available for IBD assessment

Item 42

A moderate to strong correlation between rectal bleeding and stool frequency, and endoscopic activity has been reported in UC patients (EL4). PRO-2 and -3 scale derived from CDAI diary items may be appropriate for use in clinical trials for CD (EL4).

Current evidence is not sufficient to recommend the use of available PROMs in IBD, which have to be validated before introduction in clinical practice (EL5).

[Agreement: “Agree” 83.2%, “Partially agree” 5.6%, “Neutral” 5.6%, “Disagree” 5.6%, round I]

Medically reported activity indexes are generally used to provide disease activity monitoring. Patient-reported outcome measures (PROMs) are important determinants of the illness experience, particularly from a patient’s point of view. In the era of an increasing IBD incidence with limited health-care resources, as an alternative, PROMs may help clinicians to improve follow-up strategies [183, 184]. Furthermore, The US Food and Drug Administration has indicated that patient-reported outcomes (PROs) should be the primary outcome in randomized controlled trials for CD [68].

In a recent meta-analysis, including mostly observational studies, a moderate to strong correlation between clinical activity, particularly the combination of rectal bleeding and stool frequency, and endoscopic activity in patients with UC has been shown [185]. These findings could help in prioritizing endoscopic evaluation in resource-limited areas and poor clinical follow-up assessment. However, the studies considered in the above-mentioned report were at moderate–high risk of bias.

As no validated PROMs exist for CD, CDAI diary card items have been investigated to be modified for this purpose. In a retrospective analysis, PRO-2 (abdominal pain, stool

frequency) and PRO-3 (abdominal pain, stool frequency, and general well-being) were selected from the CDAI diary cards. Scores using the two- and three-item PROs were found to positively correlate to CDAI thresholds of mild, moderate and severe disease [186].

Role of patient and public participation and engagement in IBD research

Item 43

Prioritizing the outcome relevant to patients, securely sharing data while ensuring privacy and including them in the evolving research beyond an initial enrollment, is likely to improve adherence to recommendations and patient quality of life (EL5).

[Agreement: “Agree” 94.4%,” Disagree” 5.6%, round I]

Patient perspectives are crucial for the development of guidelines on therapeutic management of IBD. The objective of increased patient participation in IBD research must be to prevent the disease and its complications, to seek innovative treatments and to access new therapeutic options, improving the patients’ quality of life and society’s awareness of the disease [187]. To do so, it is necessary to break down barriers related to the levels of security and confidentiality of the processed data, the limited resources made available, the uncertainty of how to integrate patients’ experiences into evidence-based guidelines, the time required for each individual patient and the use of a language not always accessible to all [188]. The possibility of easier updates on the progress of research and a greater communication between patients and researchers would make it possible to understand the disease from the patient’s point of view [189]. This knowledge could be used to question epistemic assumptions in medical research practices and to increase the centrality of the patient within the health-care system in general [190]. The patient’s experience is an additional perspective to the one of researchers and medical staff.

Future directions

Dedicated IBD training

Item 44

Subspecialty training in IBD surgery should take place within established high-volume multidisciplinary IBD units (EL4). IBD surgery training should include minimally invasive surgery techniques (EL3)

[Agreement: “Agree” 100%, round II]

The technical expertise required to operate on complex CD and UC, and the perioperative decision making about when to operate and whether to fashion an anastomosis or to create a stoma, require highly trained surgeons [191]. Increased experience with individualized management has demonstrated a reduction in the complications rate for patients who undergo colectomy for ulcerative colitis [192], and experience with the management of complications may lead to a higher rate of ileal pouch salvage after anastomotic leak [193].

Considering the complexity of the management of the IBD patient, surgeons in training should be exposed to effective subspecialized multidisciplinary care working in specialized IBD units [4, 8, 194, 195], collaborating as a team to optimize the integration of medical management and surgery and provide tailored and best evidence-based management for the individual IBD patients [43, 197–198].

Although several aspects of IBD like a thickened and friable mesentery, enteric fistulas, bowel perforation and intra-abdominal abscesses and adhesions make laparoscopic surgery technically demanding [199], the rate of laparoscopically managed complex IBD procedures is increasing [200]. Supervised training programs have been demonstrated to significantly decrease the length of the learning curve [201] and laparoscopic IBD surgery can be safely performed by surgical trainees in a supervised setting [202], even in the setting of complex and reoperative surgery [203].

Conclusions

The committee felt that several aspects of the general principles of management of CD and UC need further investigation.

These include the perioperative disease assessment, patient-reported outcome measures and quality of life tools specific for IBD, dedicated training, and patient participation in clinical decision making and research planning. Also, IBD in the elderly seems not to have received enough attention.

Future studies should assess these aspects.

The resulting recommendations are to be intended as a suggested pathway to follow, but they need to be applied carefully, after taking into account the individual features of each patient, and after a clear discussion with the patient about all the available options for each specific condition, and realistic expectations.

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Collaborators: Remo Andreoli, Imerio Angriman, Paola Caprino, Mattia Facchetti, Gaetano Luglio, Gilberto Poggioli, Gianluca Rizzo, Giulia Roda, Matteo Rottoli, Franco Sacchetti, Bruno Sensi, Luigi Sofo.

Steering Committee: Gianluca Pellino (coordinator), Deborah S. Keller (external advisor), Gianluca M. Sampietro (coordinator), Salvatore Leone (patient representative), Silvio Danese (external expert), Antonino Spinelli (leader), GianGaetano Delaini (SICCR IBD Committee Chair, leader), Francesco Selvaggi (SICCR President, leader).

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interests.

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Affiliations

G. Pellino¹ · D. S. Keller² · G. M. Sampietro³ · V. Annese⁴ · M. Carvello⁵ · V. Celentano^{6,19} · C. Coco⁷ · F. Colombo³ · N. Cracco⁸ · F. Di Candido⁵ · M. Franceschi⁹ · S. Laureti¹⁰ · G. Mattioli¹¹ · L. Pio¹² · G. Sciaudone¹ · G. Sica¹³ · V. Villanacci¹⁴ · R. Zinicola¹⁵ · S. Leone¹⁶ · S. Danese¹⁷ · A. Spinelli⁵ · G. Delaini¹⁸ · F. Selvaggi¹ on behalf of the Italian Society of Colorectal Surgery (SICCR)

¹ Colorectal Surgery, Department of Advanced Medical and Surgical Sciences, Università Degli Studi Della Campania "Luigi Vanvitelli", Policlinico CS, Piazza Miraglia 2, 80138 Naples, Italy

² Division of Colon and Rectal Surgery, Department of Surgery, NewYork-Presbyterian, Columbia University Medical Center, New York, USA

³ L. Sacco University Hospital Milano, Milan, Italy

⁴ Gastroenterology Unit, DEA-Medicina E Chirurgia Generale E D'Urgenza, University Hospital Careggi, Firenze, Italy

⁵ Colon and Rectal Surgery Division, Humanitas Clinical and Research Center, Rozzano, Milan, Italy

⁶ Portsmouth Hospitals NHS Trust, Portsmouth, UK

⁷ UOC Chirurgia Generale 2, Università Cattolica del Sacro Cuore, Fondazione Policlinico Universitario A. Gemelli-IRCCS, Rome, Italy

⁸ Department of General Surgery, IRCCS Sacro Cuore Don Calabria Hospital, Negrar, Verona, Italy

⁹ IBD Surgery, Azienda Ospedaliero Universitaria Pisana, Pisa, Italy

¹⁰ Surgery of the Alimentary Tract, Sant'Orsola Hospital, Department of Medical and Surgical Sciences, Alma Mater Studiorum University of Bologna, Bologna, Italy

¹¹ Pediatric Surgery Unit, Istituto Giannina Gaslini, and Department of Neuroscience, Rehabilitation, Ophthalmology, Genetics, Maternal and Child Health (DINOEMI), University of Genoa, Genoa, Italy

¹² Pediatric Surgery Department, Hôpital Robert-Debré and Université de Paris, Paris, France

¹³ Minimally Invasive and Gastro-Intestinal Unit, Department of Surgery, Policlinico Tor Vergata, Rome, Italy

¹⁴ Institute of Pathology, Spedali Civili Brescia, Brescia, Italy

¹⁵ Department of Emergency Surgery, University Hospital Parma, Parma, Italy

¹⁶ CEO, Associazione Nazionale Per Le Malattie Infiammatorie Croniche Dell'Intestino "A.M.I.C.I. Onlus", Milan, Italy

¹⁷ Division of Gastroenterology, IBD Center, Humanitas University, Rozzano, Milan, Italy

¹⁸ Department of Surgery, "Pederzoli" Hospital, Peschiera del Garda, Verona, Italy

¹⁹ University of Portsmouth, Portsmouth, UK