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ECCO Consensus Paper

Third N-ECCO Consensus Statements on the Nursing Roles in Caring for Patients with Inflammatory Bowel Disease

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Introduction

The Nurses Committee of the European Crohn's and Colitis Organisation (N-ECCO) is an active Committee of the ECCO that aims to improve access to nurse education in inflammatory bowel disease (IBD) throughout Europe and to provide a link with national nursing networking organizations. The first N-ECCO Consensus Statements were published in 2013 and sought to identify the positioning of nurses in the care of patients with IBD and to provide a consensus on the ideal standard of minimum care that patients with IBD might expect. The first update was made in 2018. The N-ECCO Consensus Statements have been widely distributed internationally, guiding IBD centers and IBD nurses to establish the most optimal quality of care in IBD. High-quality IBD care requires working

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within a multidisciplinary team (MDT). Core team members should include at least one IBD nurse, a gastroenterologist, a colorectal surgeon, a radiologist, and a dietitian. In this MDT, the IBD nurse has a clear role as coordinator between the patient and the different disciplines, with the objective of providing a holistic approach to care.[1,2] In addition to administering and monitoring treatments, IBD nurses provide education, support, counselling, and advocacy for patients. Even if the role of the IBD nurse has become more established in recent years, several differences between countries remain, including variations in education and role. In the two previous N-ECCO Consensus Statements, the statements were divided into fundamental and advanced IBD nursing. Due to the different conditions across countries, this division was removed in this update.

The overall aim of ECCO is to improve the care of patients with IBD through development of guidelines, education, and research. The N-ECCO Consensus Statements seek to realize this aim from an IBD nursing perspective, by providing statements and evidence to guide and ensure the ideal standard of care.[3,4] This third update aims to provide a framework for IBD nurses to continue delivering high-quality and evidence-based care, to consider the needs of diverse patient populations, and to include new technical tools.

Method

Two project coordinators, SR and SJ, were first selected by the N-ECCO Committee. A panel of 23 participants was then chosen from an open call, resulting in a total of 25 experts. The criteria for participant selection were primarily based on academic expertise. Other factors were also considered, such as gender balance and geographic distribution. In addition to IBD nurses, the panel also included two gastroenterologists and one dietitian. The participants were split into four working groups (WG), with one leader for each WG. Two patient representatives, selected by The International Federation of Crohn's and Ulcerative Colitis Associations, were also involved in voting and reviewing the statements. The panelists were also supported by professional librarians.

Topics were decided by the project coordinators and the WG leaders partly according to the results of a survey distributed to all N-ECCO members. The topics were then divided between the four WGs. For each topic, a research question was formulated using the Population, Intervention, Comparison, Outcome (PICO) method. The professional librarians performed literature searches on the platforms Cochrane Library, PubMed, Medline, Embase, CINAHL, PsycINFO, Scopus, and Web of Science. A search algorithm was developed where the aim was to include recent, high-quality studies, which meant that the search first focused on meta-analyses, systematic reviews, or randomized controlled trials (RCT) from 2017 onwards. If no eligible studies were identified, other experimental research could be reviewed. The identified and relevant articles were first screened for titles and abstracts by two participants for each research question. For the identified and relevant articles, full-text screenings were performed by one participant. A first draft of statements with supportive text was then developed. The statements follow the Oxford Levels of Evidence, where EL1 is the strongest evidence and EL5 the weakest (https://www.cebm.ox.ac.uk/resources/levels-of-evidence/ocebm-levels-of-evidence). All statements underwent two rounds of online voting. At the first voting round, the panelists participated and revisions were made afterwards. At the second online voting, N-ECCO national representatives and the two patient representatives also participated. For both voting rounds, an agreement of 80% or more of the participants was defined as consensus. Additional revisions were made by the WGs after the second online voting. The panelists and patient representatives then met at a face-to-face meeting to discuss and vote on the final version of all statements. The final version of all 20 statements was reviewed and approved by the ECCO Governing Board.

Statement 1. Health care institutions are recommended to establish and support specialist IBD nurse roles within MDTs. Specialist IBD nurses are associated with reduced IBD-related hospitalizations, readmissions, emergency admissions as well as improved patient satisfaction and cost-effectiveness [EL3]

Inflammatory bowel disease nurses play a key role within the MDT, and integrated nurse-led practice is now a well-established care model in IBD.[5–7] Multiple studies demonstrate that IBD nurse involvement is associated with reduced IBD-related hospitalizations, emergency department presentations, and outpatient visits.[7–14] The important contribution of IBD nurses to improved patient outcomes has been confirmed by two systematic reviews, although it should be noted that many included studies are limited by observational, single-center designs and varied methods.[5,6] Cost-effectiveness has been consistently reported, with several studies showing substantial savings at the organisational level[12–14]; one Australian study estimated an annual net savings of $570,838 AUD.[12]

Alongside these economic benefits, involvement of IBD nurses in care delivery improves patient satisfaction and quality of life (QoL).[15–17] In a nationwide audit from the U.K., patients reported improved care and valued access to specialist nurses.[16] A RCT from Germany revealed improvements in QoL among patients with lower baseline QoL scores.[18] Irritable bowel disease nurse-led services also improve clinical efficiency. For example, introduction of a nurse helpline and virtual clinic in Australia significantly reduced outpatient clinic use.[9] Irritable bowel disease nurse remote monitoring can contribute to overall health service efficiency and cost reduction.[19]

Evidence for the role of IBD nurses in supporting medication adherence is limited. One retrospective cohort study revealed reduced health care costs and improvements in adherence and persistence among patients using biological therapies who accessed a home health nurse program.[10] A second study, based on patient surveys, suggested a demand for nurse-led medication education.[20] These findings highlight the potential role of IBD nurses in medication education and support, but further research is warranted.

Statement 2. Inflammatory bowel disease nurses are recommended to be active members of the MDT and provide structured interventions, such as education, care coordination, psychosocial support, and facilitation of investigations and treatment adjustments to patients with IBD [EL3]

Patients with IBD often face multiple challenges that are related to disease activity and living with a chronic condition. These challenges are optimally addressed within MDTs. Such collaborative care improves patient-reported outcomes, reduces symptom burden, enhances treatment adherence, lowers

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hospitalization rates, and increases overall patient satisfaction.[6,8,12,18,21,22] Care delivered by MDTs and guided by clinical guidelines or consensus statements is recommended based on evidence from systematic reviews.[5,18,19]

As defined by N-ECCO and the UK consensus standards,[4,23] the IBD nurse occupies a pivotal role within the MDT, moving beyond standard care to act as the lead liaison for patients and clinicians alike. Their responsibilities range from care coordination and facilitation of investigations to psychosocial support, ensuring that the MDT functions cohesively. This central position allows the nurse to integrate the expertise of core members (such as gastroenterologists, surgeons, dietitians, radiologists, pathologists) and ancillary specialists (including pharmacists and oncologists) into a unified patient management plan.[6]

Recent evidence supports this role. A RCT compared additional care from an IBD nurse specialist with standard care. The study, which included 1086 patients with IBD, found no overall difference in disease-specific QoL at 6, 12, or 18 months. However, patients with impaired QoL at baseline did show significant improvement following the intervention.[18]

The IBD nurse contributes to efficacy of management and facilitates the delivery of high-quality care.[8,12] Single-center studies revealed reductions in unscheduled visits, enhanced self-care, and improved QoL and satisfaction with MDT-led interventions.[8,12,21,22]

Statement 3. Inflammatory bowel disease nurses should recognize and support effective psychological interventions to reduce distress, incorporate psychological screening, and refer patients to appropriate services [EL3]

Inflammatory bowel disease is associated with a significant psychological burden, including anxiety, depression, stress, and impaired health-related quality of life (HRQoL). Evidence consistently highlights a significant gap in psychological support for people with IBD, despite clear associations between psychological distress and poorer clinical outcomes, including increased emergency department visits and higher health care costs.[24]

Multiple RCTs have demonstrated the effectiveness of psychosocial interventions, such as cognitive behavioral therapy (CBT), acceptance and commitment therapy (ACT), mindfulness-based programs, and psychoeducation.[25–37] These interventions reduce anxiety, depression, disease-related worries,[28,33,38] and stress[28,38] to improve coping, HRQoL,[25] and overall well-being. Some interventions produced short-term improvements in mental QoL,[39] while others provided benefits in disease-specific concerns and psychological resilience. The value of integrating psychological care into IBD management is supported by research findings, regardless of whether the interventions were delivered as 1-day workshops or ongoing group sessions.[40]

Structured patient education and peer-support programs, particularly for adolescents and young adults,[39] also improve psychosocial outcomes and foster adaptive coping.[40] Qualitative evidence from CBT- and ACT-based studies suggests that psychoeducation can improve emotional adjustment and illness acceptance.[27,38]

Incorporating screening tools into routine assessments and facilitating access to psychological services are key areas where IBD nurses are well positioned to help, despite the relative scarcity of reports on nurse-led psychological interventions. With appropriate training, nurses could contribute to the delivery of structured psychoeducational and peer-support programs as part of a MDT. Integrating psychological screening and referral pathways into IBD management is recommended as a strategy to improve patient health and reduce the burden on health care resources.

Statement 4. Inflammatory bowel disease nurses should offer a structured support program for patients with IBD on advanced therapies, as this will improve disease management and medication adherence and assist with safety issues [EL3]

Nurses are central members of the IBD MDT, having an important role in patient education on disease course, treatment options, safety, and adherence.[41] Through nurse-led patient-centred support programs utilizing structured communication strategies, patients can become more confident and adherent to their advanced therapy, which can lead to overall reductions in health care expenditures by 10%-20%.[12,42–48] Structured communication strategies may include communication frameworks, question prompt lists, frameworks for shared decision making, use of tailored language, and visual aids.

A large study has shown that patient-support programs based on person-centred strategies improve outcomes for patients with autoimmune diseases by helping them better understand their therapies and manage a complex treatment regimen.[49] This should encompass a patient-centred approach toward the decision-making process that considers the decision-making preferences of the patient.[50]

The responsibilities of the nurse within the MDT have great importance, as the nurse is more regularly in contact with the patient, undertakes safety and drug monitoring, and is the first person the patient contacts with concerns or for further adv ice.[18,51,52]

Nurse-led telemonitoring, through telephone and web-based mechanisms, is as effective as usual care in achieving and maintaining short-term remission, while also improving adherence and clinical outcomes.[47,53–55] Proactive therapeutic drug monitoring (TDM) undertaken by nurses leads to similar clinical outcomes as those seen in reactive TDM after 1 year of follow up.[56] Therefore, nurse-led TDM strategies should be tailored to the patient and the drug being administered.[57]

Patients have increased interest in educational topics, such as diet and nutrition and specific education around treatment with biologics.[55] Research has suggested significant patient benefit in outcomes and QoL from an IBD nurse who provides structured sessions, which improve injection device knowledge, provide demonstration-device practice, and focus on both emotional and practical aspects of living with IBD. These structured sessions increase patient confidence, reduce burden on IBD nurses and the wider health care team, and improve probability of success of advanced therapy.[18,58–60]

Statement 5. Inflammatory bowel disease nurses should support and participate in an early, structured, and collaborative transition program for adolescences with IBD [EL3]

Although structured transition programs for adolescents with IBD are associated with improved clinical and patient-reported outcomes, there remains considerable variability in

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implementation across centers, and no standardized model currently exists.[61] Multiple systematic reviews and studies highlight the positive impact of transition clinics and structured interventions, including improved adherence, disease knowledge, self-efficacy, clinic attendance, and reductions in hospitalizations, emergency department visits, flares, and surgery.[62–65] A key component across successful models is the presence of a transition coordinator, who may be an IBD nurse who fulfils a role encompassing care planning, readiness assessment, education, and continuity of care.[61,62,65–67] Nurse-led coordination supports multidisciplinary collaboration, facilitates patient and family engagement, and ensures progress through individualized, age-appropriate milestones. The key to optimizing outcomes for adolescents with IBD may lie in the consistent presence of trained IBD nurse specialists acting as transition coordinators. While financial and organizational challenges currently hinder care,[67] systemic policy support should be directed toward empowering nurses to lead collaborative transition processes. Formalizing the nurse's role within future guidelines is the most effective way to address current barriers and deliver the standardized, integrated care these patients require.

Statement 6. Inflammatory bowel disease nurses should assess health risks and frailty in older patients with IBD and balance disease severity, comorbidity, and patient expectations [EL5]

The prevalence of IBD is increasing globally. An estimated 30% of patients with IBD worldwide are aged > 60 years.[68–72] Older adults (definition of older adults by age on the United Nations' criteria: individuals aged 60 years or above) with IBD can be categorized into the following two groups: "non-elderly onset" (who later transition to old age) and "late-onset" (disease onset at age ≥ 60 years). Inflammatory bowel disease nurses should be aware of the distinction between these two groups, as they may have different epidemiology, phenotypes, and outcomes.[70,71]

Although the goals of care for older adults with IBD are similar to those of younger age groups, management of IBD in the older person differs.[73,74] Inflammatory bowel disease care in the older person requires special considerations on frailty and specific disease characteristics rather than chronologic age.[69,70,72,75] Symptom control is paramount, as older patients will often choose a better QoL and are less concerned about the risks of long-term complications.[76] A comprehensive IBD nursing assessment should be balanced between disease severity, comorbidity, risk and benefits, life expectancy, and patient preferences. Nursing care must involve an understanding of not only treatments but also management of increased disposition to infections, risk of fracture, physical and nutritional frailty, incontinence, sensory loss, disturbed sleep, cognitive deficit, depression, and malignancy.[77] In the case of rectal therapies, incontinence, limited mobility, or impaired coordination skills deserve consideration.[76] Polypharmacy can also significantly interfere with the management and course of IBD.[72,78] This may influence health care costs, burden on caregivers and patients, and medication non-adherence.[77] As older patients are particularly vulnerable, nursing care should also focus on factors beyond mitigation of disease activity. Factors such as restricted mobility, depression, widowed status, and reduction of functional independence may contribute to a lower perceived physical HRQoL and social isolation.[68]

Multiple coexisting chronic diseases may warrant co-management with a geriatrician to integrate complex care and geriatric assessment as a reflection of the patient's health, including the somatic (comorbidity, polypharmacy, malnutrition), functional (daily living, physical capacity), social (support system, well-being), and mental (depressive symptoms, cognitive impairment) domains[69,75,79–81] After the age of 65 years, 17% of patients have a cognitive decline that often further complicates the diagnosis and management of IBD.[70,75,76,80] Inflammatory bowel disease nurses may support caregivers though training and education and work closely with social workers, geriatricians, and mental-health professionals to promote a person-centred approach. Unavailability or lack of reliable interactions with technology may hinder access to certain care services.[74,82] Whenever possible, in-person interactions are preferred over virtual methods.[80,82]

Statement 7. Inflammatory bowel disease nurses should recognize the importance of dietary strategies in managing patients with IBD and provide optimal and individualized dietary support [EL5]

Inflammatory bowel disease nurses play a pivotal role in patient education, early identification of nutritional concerns, and timely referral to dietitians. By measuring anthropometric parameters, using malnutrition risk-screening tools (e.g., Malnutrition Universal Screening Tool), routine monitoring of micronutrient status and hydration, and detecting nutritional deficiencies, nurses can identify patients who need further nutritional assessment. A multicenter pilot study showed that a structured nursing-led intervention combining assessment, individualized advice, referral to a dietitian, education, and follow up was feasible and significantly improved nutritional status.[83] Dietary education and support may also reduce the risk of complications. In patients requiring surgery, poor nutritional status increases the risk of postoperative complications, while preoperative nutritional support, particularly enteral nutrition (EN), can reduce this risk.[84,85]

To provide optimal and individualized dietary support, nurses should recognize the different dietary strategies as therapeutic tools in IBD.[86] The best-established dietary treatment for active Crohn's disease (CD) is exclusive enteral nutrition (EEN), which can induce clinical remission at rates comparable with corticosteroids in adult patients with CD.[87,88] However, there is insufficient evidence to support the use of EEN as an adjunctive therapy in active ulcerative colitis (UC).[89] Exclusive enteral nutrition is more effective than partial enteral nutrition (PEN) as induction therapy for CD.[90] However, when PEN is combined with the Crohn's Disease Exclusion Diet, its efficacy appears comparable to EEN. Crohn's Disease Exclusion Diet + PEN is a viable alternative for mild-to-moderate active CD.[90–95] Limited evidence supports the Mediterranean diet[96] and the Specific Carbohydrate Diet[97] in CD. In UC, the UC exclusion diet and 4 strategies to SUlfide-REduction diet[98,99] have shown promising results in inducing remission, although further studies are needed before formal recommendation.

Partial enteral nutrition is effective in patients with CD for maintaining remission.[90,100,101] Limited evidence suggests improved disease outcomes with reduced intake of red meat in UC,[102,103] reduced intake of ultra-processed foods in CD,[104] and

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adherence to a Mediterranean diet.[105,106] For patients with IBD in remission who experience irritable bowel syndrome (IBS)-like symptoms, the low fermentable oligosaccharides, disaccharides, monosaccharides, and polyols diet is recommended.[107,108]

Nutritional assessment and management should be performed by an IBD-specialized dietitian. Due to their nutritional and psychosocial risks, referral is strongly recommended particularly when restrictive diets are used. Where IBD-specialized dietitian expertise is unavailable, health care professionals with appropriate nutrition training may provide support.[86]

Statement 8. Inflammatory bowel disease nurses may play a proactive role in structured pretravel counselling for patients with IBD, including vaccination advice and treatment continuity [EL5]

Travel abroad is frequent among patients with IBD but remains clinically challenging. Between 21%-46% of patients experience diarrhea or a disease flare during or after travel, and 4%-9% require hospitalization abroad.[109,110] An international cohort of 1878 patients with IBD revealed that 28% experienced travel-associated exacerbations and up to 30% reported difficulties transporting or storing biologics during travel, particularly maintaining the cold chain.[111] High-altitude travel is also relevant, with 46% of patients reporting a flare during or after visiting destinations that require such travel.[110–112] Anxiety and uncertainty are common, as 61% of patients report travel-related health concerns and many travel during or shortly after a flare.[110,113]

Survey data reveal significant unmet needs in pretravel care that are directly relevant to nursing practice, even though interventional studies specifically assessing nurse-led counselling in IBD are currently lacking. In two outpatient cohorts, only 23% of patients actively sought pretravel medical advice despite 70%-78% reporting in the survey an interest in structured guidance.[109,110] Similarly, international studies of health care professionals, mainly nurses, revealed that only about half felt confident providing such guidance, particularly on vaccination and destination-specific risks.[109,113] These findings indicate behavioral and informational barriers for patients and providers. Preventive care is also incomplete, with 42%-48% of patients reporting that they did not receive vaccination advice before travel and up to 12% received live vaccines despite immunosuppression.[111,112,114] In addition, 32%-60% of patients travel without appropriate insurance.[110,111]

These gaps define clear areas for IBD nurses to provide structured guidance and coordinate pretravel preparation in collaboration with other health care professionals, including reviewing immunization status and contraindications; providing tailored vaccine education; advising on cold-chain maintenance and medication transport; documenting medications; addressing psychosocial concerns and red-flag symptoms; and offering hydration strategies for acute diarrheal episodes using salt–sugar or oral-rehydration solutions.[109–113] Digital-health resources may serve as valuable adjuncts to clinical care by offering supplementary support for patients during travel.[109–111,113]

Statement 9. Inflammatory bowel disease nurses should provide structured pre- and postoperative education and support for patients with IBD to improve self-efficacy, decrease psychological distress, and enhance QoL and satisfaction with surgical care [EL3]

Surgical intervention is a pivotal concern for many patients with IBD. Comprehensive, structured educational and support programs coordinated by IBD nurses and delivered in collaboration with the MDT should be considered best practice in surgical IBD care. The perioperative period is often marked by heightened anxiety, unmet informational needs, and risk of complications. Evidence supports the implementation of structured educational and supportive programs, including preoperative information on surgical procedures, recovery expectations, ostomy care (when applicable), and emotional support.[115–119] Structured education and decision aids improve patient preparedness, reduce decisional conflict, and foster shared decision making.[115–117] Participatory approaches that incorporate patient feedback are particularly important to ensure informed consent and to align surgical choices with the patient's values[115,119]

Preoperative counselling tailored to risk factors, such as obesity, immunosuppressive therapy, and disease severity, improves both perioperative safety and long-term outcomes.[120–124] Nutritional optimization as a part of prehabilitation may reduce surgical stress and shorten recovery times.[125] Postoperatively, structured follow up with individualized information and coordinated-care pathways reduced readmission rates and improved patient-reported outcomes.[126–128]

For patients with IBD undergoing stoma surgery, pre- and postoperative education is central to promoting self-management, preventing complications, and enhancing QoL.[128–130] Delivery of such care benefits from an interdisciplinary approach, with contributions from stoma care nurses, surgeons, dietitians, psychologists, and IBD nurses.[131–133] Special considerations are also needed for pregnant or pediatric populations due to hernia risk and body image concerns.[133,134] Tailored, patient-centred programs that integrate surgical expectations, ostomy education, and psychosocial support have consistently improved coping, mental health, and patient satisfaction.[135–137]

Care delivered in specialized, high-volume centers with dedicated IBD teams is associated with improved surgical outcomes and more consistent application of educational protocols.[138–140] Standardization of these interventions within Enhanced Recovery After Surgery protocols and clinical-care pathways is recommended for both elective and urgent surgery.[141,142]

Statement 10. Inflammatory bowel disease nurses should provide structured education and counselling to patients with IBD who experience fistulae, abscesses, or extraintestinal manifestations to improve treatment adherence, early complication recognition, symptom management, and psychosocial adjustment [EL5]

Inflammatory bowel disease patients who develop complications such as fistulae, abscesses, or extraintestinal

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manifestations (EIM) often face complex care pathways and emotional challenges. The ECCO guidelines highlight the importance of clear communication, patient awareness of red-flag symptoms, and coordinated referral among specialties to ensure safety and continuity of care.[143] In perianal CD, counselling should address not only medical and surgical options but also wound or stoma care, body image, and coping strategies.[144,145] Nurse-led follow up and empathetic communication promote adherence and reduce recurrence.[146,147] While education alone may have limited impact on disease activity, multicomponent and behaviorally focused programs improve knowledge, coping, and adherence.[118,148,149] Structured counselling also enhances medication safety and satisfaction.[150] For patients facing the complexities of fistulizing disease or EIMs, IBD nurses serve as the vital link to essential care. Their role is central to meeting the high informational and emotional demands of this cohort, as they are uniquely positioned to deliver the proactive education and psychosocial support necessary to manage these challenging symptoms.[151,152]

Statement 11. Inflammatory bowel disease nurses should provide tailored education and support to patients with IBD experiencing bowel urgency and fecal incontinence [EL3]

It is recommended that IBD nurses provide structured, individually tailored education and support to patients with IBD experiencing bowel urgency and fecal incontinence.[153–155] This may include information on underlying mechanisms, pelvic-floor exercises, bowel retraining, dietary advice, and emotional support. Structured self-management programs should consider patient preferences and symptom profiles.[154,155]

Bowel urgency and fecal leakage are distressing and often underreported symptoms that affect 31%-74% of patients with IBD, often irrespective of disease activity.[153] As disclosure is frequently hindered by stigma, embarrassment, and perceptions of an untreatable condition, this emphasizes the need for supportive, nurse-led dialog to normalize discussion and facilitate timely interventions.[153,155]

Structured nurse-led education and support can improve continence outcomes, self-efficacy, and psychological well-being. Usual care typically consists of routine monitoring or general advice without structured intervention.[155] Tailored strategies remain essential, as no single approach benefits all patients. The IBD nurse may also provide information on diagnostic methods such as anorectal manometry or MR-defecography. Collaboration with physiotherapists or psychologists may be required for interventions such as pelvic-floor therapy, biofeedback, or psychological support.[154,155]

Randomized controlled trials have highlighted both the promise and the challenges of self-management programs. The IBD BOOST trial evaluated a digital facilitator-supported program and revealed no significant benefit over usual care in QoL or symptom relief, although the adherence rate was low (57% completed ≥4 sessions).[155,156] A trial of a self-management booklet identified barriers to participation, including reluctance to self-identify as "incontinent," with patients preferring terms such as "urgency" or "leakage".[157] Sensitive communication is therefore critical.[153,157]

Non-invasive strategies that are effective in the general population (pelvic-floor physical therapy, biofeedback, and dietary modulation) are increasingly supported in the context of quiescent IBD.[157] Both a systematic review and an expert opinion emphasized the value of simple, safe, and stepwise approaches, starting with education, bowel modifiers, and physical therapy and progressing to minimally invasive interventions when needed.[154,158]

Nurse-delivered, multimodal continence programs show significant promise, even though IBD-specific evidence is currently limited.[158] Integration of psychological perspectives is also critical, as patients with IBD may benefit from understanding how cognitive and emotional responses to chronic symptoms can perpetuate distress. Framing this within the brain–gut axis may reduce stigma and promote symptom self-management.[159]

Statement 12. Inflammatory bowel disease nurses should assess and manage pain in patients with IBD through structured counselling, supporting coping strategies, and facilitating access to effective and adjunctive therapies [EL3]

Although several studies have examined the role of IBD nurse-led care on pain management, the evidence remains inconclusive. While some findings suggest potential benefits,[160–163] such as reduction in analgesic use, a RCT[156] failed to demonstrate statistically significant improvements in pain control, pain-related disability, or self-efficacy. These findings highlight the need for further prospective research with larger sample sizes and longer follow-up periods to determine the effect of IBD nurses on pain outcomes. IBD nurses may contribute to pain management through structured counselling and tailored educational interventions that help patients better understand their symptoms, identify triggers, and manage their condition. Through these interactions, nurses support individuals in developing practical coping strategies, such as relaxation techniques, pacing of daily activities, problem-solving skills, and methods to manage stress and anxiety that can reduce the perception of pain and improve overall self-management. Additionally, they can facilitate access to adjunctive therapies (e.g., acupuncture) and coordinate multidisciplinary resources, including psychological support or other appropriate services.[15,22,164–168] A RCT confirmed a greater improvement in QoL in patients managed with IBD nurse support compared with those receiving standard care.[156] This effect was statistically significant in the subgroup of patients with coexisting IBS, further supporting the rationale for implementing IBD nurse-led interventions to improve patient-reported outcomes. In addition to clinical benefits, IBD nurse involvement has demonstrated cost-effectiveness, with reported health care savings of £746 per patient per year of follow up.[169] Although evidence for direct effects on pain remains limited, the proactive role of IBD nurses in assessment and coordination positions them to support patients experiencing chronic pain and to identify those who may benefit from specialist interventions.[159,170] Further large studies are needed to establish the role of the IBD nurse in chronic pain management.

Statement 13. Inflammatory bowel disease nurses should assess and manage fatigue in patients with IBD through structured counselling, supporting coping strategies, and facilitating access to effective therapies [EL3]

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Fatigue is one of the most common and burdensome symptoms in IBD and affects 40%-50% of patients in remission and up to 80% during active disease.[171,172] Evidence from small RCTs, feasibility studies, and systematic reviews indicates that multi-component, patient-centred educational and counselling interventions and electroacupuncture can improve fatigue-related outcomes.[156,173–180] Psychoeducation and CBT, including mindfulness-based approaches, consistently reduce fatigue severity and impact relative to usual care.[173,174] Systematic reviews, including Cochrane analyses, revealed that non-pharmacological interventions, such as CBT, mindfulness-based CBT, sleep and activity guidance, and energy-conservation strategies, produced small-to-moderate improvements in fatigue and related outcomes, although sample sizes and methodologies varied.[156,175–180] Benefits may also be sustained after mindfulness-based interventions.[181,182] Routine fatigue screening using validated tools (e.g., the IBD-Fatigue Scale)[183] is recommended to identify and monitor symptom severity and impact and to inform targeted management.

Behavioural programs incorporating pacing, graded activity, and lifestyle modification improve perceived energy, functioning, and self-management confidence.[184–186] Such interventions enhance coping strategies and fatigue-related knowledge, contributing to improved self-efficacy.[173,174,178] Psychological benefits, including reductions in anxiety, depression, and stress, are reported consistently, alongside improvements in HRQoL.[180,182,185,187,188] Sleep management and nutritional education are emerging components of holistic fatigue interventions. Sleep-focused strategies address a recognized mechanistic contributor to fatigue,[189] while nutrition screening and guidance may further support self-management and energy regulation.

These interventions are safe and well accepted, with attrition rates comparable to usual care.[156,175–179] While pharmacological approaches, such as high-dose thiamine, have shown promise in small trials,[190–193] these sit outside the non-pharmacological counselling interventions considered here, although they support inclusion of nutrition screening and education within broader programs. However, current evidence is limited by small sample sizes, heterogeneous content, and predominant recruitment of patients in remission. Effects are promising but modest, and further research is required to establish long-term benefits and applicability in active disease. By integrating fatigue management into routine assessments, IBD nurses act as the primary drivers of patient-centred care, ensuring that these specialized programs are both accessible and effective.

Statement 14. Inflammatory bowel disease nurses should routinely assess sexual function, provide counselling and education, and facilitate referral of patients experiencing sexual dysfunction to a specialist [EL3]

Inflammatory bowel disease nurses play an important role in the routine assessment of sexual function, particularly among perioperative patients and those experiencing active disease, as early identification can enable timely diagnosis and treatment of sexual dysfunction.[194] Preliminary evidence suggests that psychological interventions may be beneficial in alleviating sexual dysfunction. An 8-week, IBD-specific CBT program delivered by a clinical psychologist demonstrated significant improvements in sexual functioning following the intervention period.[195] In contrast, a group cognitive behavioral psychotherapy intervention showed no significant effect on sexual function; however, the RCT may have been insufficiently powered to detect meaningful changes.[30] An observational study indicated that adherence to a Mediterranean diet, along with better physical and mental health, was protective against sexual dysfunction, particularly in females.[196] Supporting this, a multifaceted wellness program incorporating virtual healthy living classes and wellness coaching produced a significant positive effect on sexual function in women with IBD.[197] Although the evidence remains limited, IBD nurses should routinely assess sexual function using validated, gender- and IBD-specific tools and provide counselling and education on healthy lifestyle choices for patients experiencing sexual dysfunction and facilitate referrals to appropriate specialist members of the MDT (e.g., psychologist, sexologist, specialists in pelvic floor dysfunction or gynecologists), as appropriate and if available.[194]

Statement 15. Inflammatory bowel disease nurses may address preconception and fertility concerns and provide accessible education to increase reproductive knowledge and improve emotional health in patients with IBD [EL4]

Suboptimal patient knowledge contributes to pregnancy avoidance, voluntary childlessness, and medication discontinuation during pregnancy.[198] Reported evidence recommends proactive pre-conception counselling, preferably starting at the time of IBD diagnosis in patients of childbearing age and 3-6 months prior to attempts at conception.[199] Fertility concerns, fetal safety of medications, IBD heritability, and disease control should be discussed.[198]

As disease heritability is one of the greatest concerns of people with IBD, this topic requires special attention during preconception counselling.[200] Although a positive family history is not the only consideration, the risk of IBD development in the child is increased (particularly for CD) and is much greater when both parents are affected.[199,200]

Achieving and maintaining remission at the time of conception and during pregnancy reduces the risk of complications for both mother and fetus.[201] The IBD nurse should highlight the importance of disease monitoring and offer timely reviews to minimize relapses and early referral to the MDT for therapy adjustment.[201,202] Educational intervention provided by the IBD nurse on IBD and pregnancy promotes reproductive knowledge and IBD medication adherence during pregnancy.[194]

A Korean study revealed that a pre-conception educational program developed and provided by nurses and including small-group sessions and individual tele-coaching can improve IBD-related pregnancy knowledge and confidence in IBD self-management and was effective in relieving IBD-related anxiety.[203]

Most IBD medications do not impact fertility; only sulfasalazine can cause reversible sperm abnormality.204 Preconception counselling should address the negative impact of disease activity on fertility; advice on the importance of achieving clinical remission, which may improve chances of conception in both male and female patients, should be provided.[202]

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Ileal pouch–anal anastomosis is often cited as a risk factor for infertility, particularly in females.[199] A laparoscopic approach seems to be associated with lower infertility, most likely due to reduced pelvic adhesions.[199] The IBD nurse should advocate for women with pregnancy desire to discuss surgical options within the MDT.[205] Laparoscopic surgery and ileorectal anastomosis should be considered in suitable patients after careful evaluation as a fertility-sparing option.[205]

Once pregnant, women with IBD have comparable chances of achieving a live birth compared with women in the general population who underwent assisted reproductive technology.[199] The IBD nurse may identify the need for referrals for fertility therapy during the nurse consultation, which may subsequently be raised with the medical team.[206]

Statement 16. Inflammatory bowel disease nurses should inform patients with IBD who are pregnant on the impact of disease activity, delivery mode, postpartum, breastfeeding, and newborn vaccination [EL4]

Pregnant or postpartum women with IBD on advanced therapies should be managed by health care professionals with relevant expertise on IBD and pregnancy.[207] The care should be coordinated between obstetrics and the IBD unit to ensure that the patient does not receive conflicting medical advice from the respective services.[207] A joint pregnancy clinic with a dedicated gastroenterologist, obstetricians specializing in high-risk pregnancies, colorectal surgeons, IBD nurses, dietitians, and midwives is advised for the management of women with IBD presenting features associated with poor disease course.[202] The IBD nurse has a fundamental role in liaising with the gastroenterologist and obstetrician whilst supporting the patient.[199,206]

Dedicated in-person or online educational programs improve not only the patient's IBD-specific pregnancy knowledge and medication adherence but also reduce anxiety about actively facing pregnancy.[201,203] Inadequate knowledge is associated with riskier illness-related behaviors and fear[201]; topics to be addressed should include drug safety, delivery mode, breastfeeding, and newborn vaccinations.[208] Most IBD medications, including advanced therapies, are considered safe and can be continued during pregnancy to maintain remission.[199] However, since specific IBD medications (e.g., methotrexate, Janus-kinase inhibitors, and sphingosine-1-phosphate receptor modulators) are contraindicated in pregnancy, a thorough medication review prior to conception is recommended.[202]

Models of shared decision making should be employed when counselling patients regarding mode of delivery, as this will reduce patient uncertainty and anxiety.[207] Vaginal delivery is recommended provided there are no obstetric contraindications.[199] Caesarean section would only be considered in the presence of an ileoanal pouch anastomosis and complex active perianal disease.[199]

Breast milk provides ideal nutrition, has positive effects on the immune system of the newborn, and may protect against development of IBD.[207] The IBD nurse should encourage breastfeeding and provide advice on medication safety.[200] Drugs that are considered low-risk during pregnancy are also considered low-risk during breastfeeding and thus can be continued.[202]

Inactivated vaccines are recommended according to national guidelines, as their effectiveness and safety seem to be favourable.[199] In children exposed in utero to biologics, live-attenuated vaccines should be withheld within the first year of life.[199] Improving patient knowledge and confidence for better disease management during pregnancy and the postpartum period should be the focus of future studies and specifically assess the effects of structured education programs delivered by IBD nurses.

Statement 17. Inflammatory bowel disease nurses should create a welcoming and inclusive environment for all patients, provide education that respects sexual orientation and gender identity, and help sexual and gender minority patients access the multidisciplinary care and support needed [EL5]

Inflammatory bowel disease nurses play a key role in fostering an inclusive environment for sexual and gender minority (SGM) individuals with IBD. Limited evidence exists regarding SGM individuals with IBD, as sexual orientation and gender identity (SOGI) data are often not collected or reported, thereby restricting disease-related insights in this cohort.[209,210] However, emerging research[211] indicates that cisgender men, cisgender women, and transgender and gender-diverse individuals with IBD may experience sex or gender differences (or both) in core symptoms, such as fatigue and anxiety, suggesting that tailored symptom management may be warranted. Furthermore, higher mental-health comorbidity has been reported among SGM individuals with IBD, which likely impacts QoL and care engagement.[212] It is recommended that IBD nurses incorporate routine, sensitive SOGI data collection; use gender-affirming, inclusive language and communication; provide education that respects SOGI; and help SGM patients access the multidisciplinary care and support needed (e.g., for fertility or surgical planning). However, IBD clinicians require education and training in gender-affirming care, and further robust research involving inclusive samples is warranted.[213]

Statement 18. Inflammatory bowel disease nurses should identify and regularly assess the evolving educational needs of newly diagnosed patients with IBD, provide timely and ongoing individualized education, and facilitate peer support [EL3]

Inflammatory bowel disease nurses play a pivotal role in identifying and regularly assessing the evolving educational needs of newly diagnosed patients with IBD, providing timely and individualized education, and facilitating peer support. Only two RCTs have specifically evaluated the effectiveness of educational interventions in newly diagnosed patients with IBD. A small feasibility study found that a web-based educational resource focusing on food-related issues led to improvements in food-related QoL and some psychological outcomes in patients diagnosed within the past year.[214] Another study evaluating an IBD nurse-coordinated, multiprofessional, group-based education intervention did not demonstrate significant differences in psychological well-being between the control and intervention groups; however, it was highly valued by patients diagnosed within the previous 2 years.[215]

Research[216–219] including newly diagnosed patients with IBD in a wider sample has evaluated educational videos,[216] adaptation training,[217] integrated medical and psychological/

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psychosocial group-based intervention programs,[218] and a therapeutic education program[219]; however, the samples were not stratified by disease duration. A subgroup analysis demonstrated a statistically significant improvement in HRQoL and coping ability in those with a short disease course (≤3 years) after receiving an education and group therapy intervention.[218] A standardized therapeutic educational program also found a significant increase in skills and knowledge compared with the control group in a large multi-center RCT that included patients with a recent diagnosis (<6 months).[219]

Inflammatory bowel disease nurses, as part of the MDT, should provide timely and ongoing individualized education that incorporates peer support and addresses the unique needs, preferences, and goals of newly diagnosed patients with IBD. The limited evidence base[118] highlights the need for IBD nurses to contribute to knowledge generation by formally evaluating educational programs implemented in practice using scientific methods, such as experimental or quasi-experimental methods and standardized and validated patient-reported outcome measures.[220]

Statement 19. Inflammatory bowel disease nurses are recommended to use individualized digital-health technologies as supportive resources to enhance treatment adherence and reduce hospital visits [EL4]

Digital-health technologies are increasingly being adopted to support clinical practice, as evidenced by the growing body of high-level research in this area. An umbrella review[221] of nine systematic reviews of RCTs found that digital-health technologies do not lead to better clinical outcomes in maintaining IBD remission or reducing relapse rates; however, these technologies could be used as an adjuvant resource that contributes towards treatment adherence and reducing hospital visits. There was considerable heterogeneity in the digital interventions evaluated, including web-based applications, telephone consultations, emails, text messages, videos, remote-monitoring platforms, tele-education, virtual clinics, and online self-management programs. Evidence suggests that digital-health technologies do not significantly affect disease activity[222–226] or remission rates.[222,224] Nevertheless, some improvements have been reported in QoL[222,224] and disease-related knowledge,[224] with stronger evidence supporting improvements in medication adherence[223,226–228]and reductions in hospital visits,[222,225,226,228,229] including outpatient and emergency visits, albeit with variable effect sizes.[221] The substantial heterogeneity across studies and high risk of bias highlight the need for standardization of digital interventions and for more robust, large-scale RCTs to confirm their effectiveness and identify patient subgroups most likely to benefit. The adoption of digital-health technologies in IBD care is expected to grow with the emergence and integration of artificial intelligence into these tools. Artificial intelligence,including generative and machine-learning models, is evolving as a transformative tool in IBD care through improved prognosis and personalized care. However, clinical integration depends on rigorous validation, standardized protocols, data transparency, and expert oversight to ensure reliability and safety.[230–237] Furthermore, while no harmful effects of the use of digital-health technologies have yet been reported, concerns regarding equitable access, data security, and potential effects on clinical decision making require ongoing investigation.[221] As the patient's first contact, the IBD nurse provides advice and education and coordinates care by using different digital-health technologies, such as virtual clinics, videos, and tele-education.

Statement 20. Nurses new to IBD should engage in structured, competency-based mentoring programs to improve job satisfaction, retention, and patient outcomes [EL4]

The principles of structured and guided learning, which are fundamental to effective mentoring, are well-supported in the literature despite a current lack of direct evidence focused specifically on formal IBD nursing mentorship. Mizuno et al.[238] demonstrated significant improvements in IBD-related knowledge through an e-learning educational program based on the Attention, Relevance, Confidence, and Satisfaction instructional design model, with high participant satisfaction and usability ratings. Similarly, Berry et al. reported that brief, targeted educational interventions significantly improved validated IBD knowledge scores (CCKNOW) among nurses, regardless of delivery modality.[239]

Moreover, Ohue and Menta[240] showed that mentorship interventions incorporating CBT techniques effectively reduced burnout and turnover among nurses, highlighting the psychological and professional benefits of structured mentoring. These findings reinforce the importance of mentoring in fostering emotional well-being, self-efficacy, and retention factors closely linked to the delivery of safe, high-quality patient care.

The potential for structured mentoring to improve patient outcomes is driven by its ability to bolster the competence and well-being of the IBD nurse. Current evidence suggests that these frameworks ensure more consistent and confident nursing care, representing a vital investment in the clinical workforce even where direct IBD-specific data remain limited.

Conclusion

The landscape of IBD management is consistently evolving and the role of the IBD nurse is clearer and more established. The N-ECCO Consensus Statements provide a framework for IBD nurses regardless of geographic location to continue delivering high-quality and evidence-based care to IBD patients.

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Supplementary material

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Conflicts of interest

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Data availability statement

The data underlying this article are available in the article and in its online Supplementary material.

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