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CONSENSUS/GUIDELINES

N-ECCO Consensus statements on the European nursing roles in caring for patients with Crohn's disease or ulcerative colitis

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1. Introduction to N-ECCO Statements

N-ECCO (Nurses-European Crohn's & Colitis Organisation) has been an active member of ECCO since 2007, with the purpose of providing nurse education and the opportunity for nurses to network internationally. N-ECCO aims through its activity to improve nurses' knowledge of Inflammatory Bowel Disease (IBD), share best practice and thus improve the quality of care accessed across Europe by patients with IBD.

It has long been acknowledged in N-ECCO that nurses across Europe perform and provide varying roles in caring for patients with IBD, given the country-specific variances in role, title, salary and level of training.

1.1. Aims

The intentions of the N-ECCO Consensus statements are to identify the positioning of nurses (adult and paediatric) 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, irrespective of the level of nurse training, title or country. The 'ideal' standard of nursing care was deemed an accurate measure and appropriate by the group in order to provide a standard for all nurses working with people with IBD.

1.2. Methods

The N-ECCO Committee agreed the need for the consensus statements on the nurses' role in June 2011. Following the Standard Operating Procedure (SOP) of ECCO (www.ecco-ibd.eu/) a proposal for guidelines, along with draft contents for the statements, was submitted to the Governing Board. This was approved in November 2011, with a recommendation to conduct a survey to gain a clear understanding of the current situation of nurses within Europe in caring for patients with IBD. The survey was developed and refined

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within the N-ECCO committee in time for N-ECCO February 2012, when all attending nurse delegates were asked to complete it. Results of this survey will be published separately.

There was an official call from the ECCO Office for nursing participants to be involved in the N-ECCO Consensus in March 2012. Fifteen nurses were selected by the N-ECCO Committee, following self-nomination, given that they all had adequate experience of nursing in the field of IBD. In April 2012, nurses were allocated into one of four working groups to reflect adequate country variances, with each group chaired by a N-ECCO Committee member. Between April & June 2012, each Consensus group was given a defined section of work, based on the draft content at that time:

(1) Fundamental IBD Nursing
(2) Advanced IBD Nursing
(3) Nursing care for particular situations (e.g. fatigue, pregnancy, incontinence)
(4) The Benefit of an IBD Nurse.

Each group performed an electronic literature search using PubMed (1996–2010), MEDLINE (1966–2010) and EMBASE (1980–2010), via the OVID platform. The search was conducted from the inception of the databases to November 2012. The literature review deployed the recommended grades and levels of evidence according to the Oxford Centre for Evidence Based Medicine[1] as per the ECCO SOP. Nursing studies tend to be qualitative, focusing on exploring patient's issues and experiences, so it is important to acknowledge that the Oxford system of grading evidence gives greater weight to empirical evidence and does not rate qualitative research highly. Although there are grading systems specific to qualitative research, these do not form part of ECCO's SOP and were therefore avoided.

In June 2012, a one day meeting took place with all consensus group members present to discuss the evidence and to draft preliminary statements based on the literature. Between June & September 2012, each group finalised their statements and supporting text. This was in turn reviewed at the N-ECCO Committee Meeting in October 2012. A further one day meeting took place in November 2012 to vote on each individual N-ECCO Consensus statement. Each of the 26 Consensus statements were voted upon and, in line with the ECCO SOP, agreed by greater than 80% of the groups' vote. Further to this meeting an editorial board consisting of four group members (M. O'Connor, P. Bager, J. Duncan, J. Gaarenstroom, L. Younge) refined the supporting text for the corresponding author and each of the Consensus statements.

1.3. Format

The Consensus statements have been divided into three sections:

(1) Fundamental Inflammatory Bowel Disease Nursing
(2) Advanced Inflammatory Bowel Disease Nursing
(3) The Perspectives of IBD Nursing.

Fundamental IBD Nursing identifies the basic nursing care required to address the needs of patients with IBD. The Consensus group suggests that these needs can be addressed by nurses working in various settings. The statements within this section also pertain to those working at an advanced level, as the Consensus group acknowledged that fundamental nursing care & skills were developed and refined with experience in advanced nursing practice.

The section on Advanced IBD Nursing refers to those nurses who, with experience, training and/or education, are practicing advanced nursing care. The statements within this section aim to identify the role of the advanced nurse, acknowledging the expertise in care and management of caseloads of patients with IBD, whilst also recognising the limitations relevant to this level of nursing care.

The section on the Perspectives of IBD Nursing acknowledges the value of IBD nurses and identifies that there is scarce evidence available within literature to support the value of IBD nurses in improving patient outcomes.

2. Fundamental Inflammatory Bowel Disease (IBD) Nursing

2.1. Definition and requirements

N-ECCO Statement 2A

Nurses in contact with patients with IBD working in any setting, need to have basic knowledge of the diseases, know the difference between Crohn's disease and ulcerative colitis, and appreciate the importance of establishing timely therapeutic interventions. Awareness of the key diagnostic strategies and of the main medical and surgical options available in the management of IBD is recommended [EL3].

Inflammatory Bowel Disease (IBD) is an umbrella term given to the life-long ('chronic') bowel diseases of which Crohn's disease (CD) and ulcerative colitis (UC) are the predominant forms. Although the causes of IBD are unknown, it is recognised as an immune-mediated disease, possibly precipitated by a mixture of genetic and environmental factors which may include fastidious childhood hygiene, smoking, or drugs (such as anti-inflammatories, the contraceptive pill, or antibiotics).[2–4] IBD commonly presents in adolescence or young adulthood, and follows a currently unpredictable relapsing and remitting course.

UC is confined to the rectum and colon. Originating in the rectum (proctitis), it can extend proximally to the sigmoid and descending colon (left-sided colitis), or the entire colon (pan, or extensive colitis).[5] The inflammation is continuous and limited to the mucosa. Symptoms include rectal bleeding and passage of mucus and faecal urgency leading sometimes to incontinence. The location and severity of disease activity determines the choice of therapy.

CD affects the gastrointestinal (GI) tract anywhere between mouth and anus. It occurs most commonly in the ileocaecal region, followed by the colon. The inflammation is