N-ECCO survey results of nursing practice in caring for patients with Crohn's disease or ulcerative colitis in Europe

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Nursing survey; European nursing practice; Crohn's disease; Ulcerative colitis; Inflammatory bowel disease nursing

Abstract

Background and aims: The difference in nursing roles when caring for patients with inflammatory bowel disease varies across Europe with different levels of responsibility. This might vary widely from country to country and even hospital to hospital depending on the local requirements of the patients and the gastroenterology team. This survey was developed to assess the current nursing practice across Europe.

Methods: A total of 220 nursing delegates who attended the N-ECCO Meeting and School in 2012 were invited to complete a survey. The survey consisted of 11 questions about the role and responsibility of nurses in the care of patients with inflammatory bowel disease.

Results: Of the 220 European nurses, 192 responded (87%). A majority (61%) came from 5 European countries, most were between 30 and 50 years old, 73% worked in public hospitals and 68% were involved in adult care. The level of education varied equally between certificate level, degree level, diploma level and masters' level. The nurses' level of experience, above that of the level of education, was the main factor in determining whether to offer advice or not to the patient, independent of a doctor ($p < 0.01$).

Conclusion: This survey has provided an understanding of the nursing role in the care of patients with IBD across Europe as well as Australia, Canada and Israel. It demonstrates that the role of...
1. Introduction

The inflammatory bowel disease (IBD) nursing role is increasingly recognised as a foundation in robust IBD healthcare services and is well established within the multidisciplinary team.1–3 The role has developed considerably within many countries, most notably within the UK and Canada over recent years.4,5 From communication through the Nurses European Crohn’s and Colitis Organisation (N-ECCO) networking meetings in recent years it seems that IBD nurses have a wide clinical role in caring for patients with IBD. These include providing telephone access (advice lines or helplines) to allow sick patients rapid access to specialist advice, case management during clinic reviews, supporting patients throughout their diagnosis and treatment, co-ordinating safe management of patients on immunosuppressant medications and access to other therapies (such as biologics), performing endoscopic procedures and developing self-management strategies.6–11 Along with a clinical role, many nurses also are involved in management, education, research and further service development12,13 as part of the role of an advanced nurse.

N-ECCO has been an active member of the European Crohn’s and Colitis Organisation (ECCO) since 2007, providing education and networking opportunities for nurses with the annual N-ECCO Meeting and School. N-ECCO has long acknowledged the difference in nursing roles across Europe with the level of responsibility and nursing care varying widely from country to country and even hospital to hospital depending on the local requirements of the patients and the gastroenterology team. Nurses in the UK support patients’ with Crohn’s disease (CD) and ulcerative colitis (UC) in many different settings within acute, general and teaching hospitals.13

This survey was developed to assess the current nursing practice across Europe in caring for patients with CD or UC. It was anticipated that this survey would provide clarity on the current positioning of nurses across Europe in the care of patients with IBD, to enable closer collaborative working in terms of clinical services, education and research, as identified in the N-ECCO consensus statements.14

2. Materials and methods

2.1. Survey development

The draft survey was developed with 11 main questions along with a free text area for further comments (see survey tool in Appendix A). In October 2011, following review and ratification by the N-ECCO Committee and ECCO members, amendments and additions to the survey were made. As English is not the first language of many nurses attending N-ECCO, the survey was tested through a pilot study in which the participants from different countries were asked to complete. The survey was distributed electronically, in its entirety, with requests to critique its structure and wording. The pilot study was completed by 10 N-ECCO National Representatives in November 2011 and all provided feedback on ease of use and identified suggestions for improvements. The survey was finalised in January 2012 and printed in English only. This final survey consisted of 11 questions about the role and responsibility of nurses in the care of patients with IBD and allowed for a comprehensive understanding of the individual’s role, area of work, and level of responsibility.

The survey was presented in three sections.

Part 1 established demographics of the nurses’ current role, age, sex and country of work.
Part 2 requested information on nurses’ current level of education.
Part 3 explored the professional roles of the surveyed nurses providing information on the specific details of their work, role and level of autonomy.

The survey was disseminated for completion to all nurses who attended the N-ECCO School and N-ECCO Network Meeting in February 2012 in Barcelona, Spain.

3. Data analysis and statistics

The initial analysis of the collected data was undertaken by the ECCO Secretariat. Summary statistics and rank sum tests were performed using Stata 12 (StataCorp. 2011. Stata statistical software: Release 12. College Station, TX, USA).

4. Results

A total of 220 nursing delegates who attended the N-ECCO Meeting and School in Barcelona, Spain in 2012 were invited to complete the survey. Of these 192 responded (87%). Seven nurses did not state their nationality and 10 nurses came from outside Europe. Data are calculated for all responders regardless of nationality details.

5. Demographics and work place

Nurses originated from 23 different countries (see Table 1). A majority 116 (61%) were from five European countries; comprising of the UK, Netherlands, Denmark, Spain, and Ireland. For all countries, a large majority of the nurses were females (91%), although there was some country variation in the proportion of females versus males. Most nurses were from the age groups 30–40 years and 41–50 years old.

The vast majority (73%) worked in a public hospital; with a further 17% working in an academic centre, 5% in a private hospital and 5% ticked other.
Table 1: Responders demographics, education levels and work related data – from Europe, other countries and missing.

<table>
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<tr>
<th>Country</th>
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<th>Gender (% males)</th>
<th>Age groups (%), years</th>
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*The highest level of education used.*
6. Education and experience

A total of 165 nurses (86%) completed details of their education level. The country specific distribution is shown in Table 1. Thirty-three (20%) had completed a certificate level of training, 46 (28%) a diploma level education and 50 (30%) a degree level education. A further 36 (22%) had completed master's level nursing education, and this is likely to be as post-registration training. Specific IBD Nursing education was reported as available in the UK, Austria, Czech Republic, Finland, Germany, The Netherlands, Spain and Sweden. Additionally, IBD nursing education was reported as being under development in Australia, Belgium and Denmark.

Of the respondents, 130 (68%) identified that they were an adult IBD nurse, 5 (3%) were paediatric IBD nurses, and 29 (15%) were research nurses, 10 nurses (5%) stated other, but did not state in the free text as to the nature of their nursing role. Finally 57 (30%) also stated that they were a gastroenterology nurse who cares for IBD patients. In addition 37 (18%) ticked 2–3 answers suggesting some have dual roles.

There was a wide array of years of experience within IBD (see Table 1). Only 8% of the respondents reporting to be in post less than 1 year, 38% has been in post for between 1 and 5 years, 30% between 6 and 10 years and a further 24% in post for greater than 10 years.

7. Professional role

Most nurses reviewed between 16 and 25 patients per week. The main contact for 90% of the nurses with patients was direct clinical contact (face to face). A further 75% reported that they reviewed patients over the telephone, 32% in research, 43% within endoscopy and 45% reviewed patients in wards (in-patient setting).

The specific role of the nurse within this survey has been divided according to the different clinical activity. Eighty-two percent of nurses provided telephone access for patients. A further 81% coordinated access for patients to therapies (including biological therapy and immunomodulator) and of this 63% also directly administered these therapies. Twenty-two percent performed endoscopic procedures. Seventy percent were involved in providing patient education. Finally 45% had a role in staff education. As the results indicate, many nurses had several tasks within IBD nursing.

8. Clinical responsibilities

Table 2 compromises the proportion of nurses who were able to advise patients without consulting a doctor, breaking down the role into its component parts. The majority of nurses were able to do the following independently: assess the patients’ condition and advise on disease management; provide information on CD and UC; discuss the medical management of IBD; educate the patients regarding surgical management of IBD and provide information on test results. The proportion of nurses able to do so was widely distributed regarding education, work place and years of experience.

It appears that the nurses’ level of experience, above that of the level of education, was the main factor in determining whether to offer advice or not to the patient, independent of the doctor (p < 0.01).

A minority of nurses reported that they were independently advising patients to alter their medication dosages by adhering to local guidelines/protocols, by following national/European guidelines and 20% reported that they had completed a non-medical prescribing course allowing them to legally independently prescribe.

9. Discussion

The survey confirms the wide variety of roles, responsibilities and level of autonomy IBD nurses hold across Europe. A large percentage of nurses are able to independently assess and offer advice to patients regardless of their level of education, many provide care via clinic reviews, telephone contact and access to therapies. Ensuring access to care has proven to be an important domain of the IBD nurse. The IMPACT survey reported this as an area for concern and there is national evidence that access to care within 7 days for relapse is significantly higher with an IBD nurse in post.15,16 These services are fundamental to the role of an advanced specialist nurse3,4,17 as seen in other chronic diseases, including rheumatology nursing18 and diabetes nursing.19

The level of experience of the nurses who participated within the survey, 38% having 1–5 years experience, suggests that IBD nursing is still within its infancy in many European countries. This correlates with UK data over the past decade, with the IBD Audit demonstrating that 61% of hospitals had an IBD specialist nurse in 2008 but that this had increased to 82% in 2010.1 Certainly within the UK, this increase in advanced nursing posts within IBD can be attributed to changes in the healthcare system20 along with support from the nursing regulatory body21 and as a result of campaigning by the national patient body for patients with CD and UC.

Over a third of nurses were advising patients to independently alter their medications. This was only being undertaken by nurses following local, national or European guidance or by those whom had completed non-medical prescribing. The practice of nurses altering patients’ medication dosages based on locally agreed hospital policies is recognised22 but it is essential that nurses are cognisant of their professional regulation in this area of practice and their legal parameter which is country specific. Of course, it should be acknowledged that, given the diversity of nurses from such a wide number of different countries who have completed this survey, it is likely that the professional regulation and legal parameters in each geographical area will differ. Nurse prescribing is becoming a widely integrated aspect of health service delivery in many countries and is safe and appropriate when delivered within the proper legal framework.23,24

A divide was identified in the nurses’ education levels. Within the UK, the nursing body Royal College of Nursing, has specified that advanced nurses undertaking such roles as clinical nurse specialist should be educated to Bachelors or Masters level education.17 However this recommendation is not compulsory, and despite ongoing reforms, many countries have faced difficulties in implementing clear pathways in Bachelors and Masters level education25 and this is perhaps the reason why only 13% of the UK IBD nurses hold a Masters degree.13

Education to Masters Level in nursing purports to lend credibility to the IBD nurse role, the individual capability of the nurse enhances the attribution of autonomous skill, these
nurses are in a better position to promote evidence-based practice,\cite{26, 27} and provide a higher level of care.\cite{28} Despite the many positive gains reported in the literature of higher level nurses, a systematic review suggests that these relative gains are directly attributed to the personal qualities of the nurse which provide direct patient benefits, but the overall evidence is scant.\cite{29}

One finding from the survey was that the relationship between experience and making autonomous decisions regarding patient care was significantly more than the nurses’ level of education. This suggests that experiential learning, defined as the process whereby knowledge is created through the transference of experience,\cite{30} plays a greater role than the level of education.

As education and networking opportunities for nurses continue to develop within the speciality of IBD across Europe and patient support for the role increases through European organisations such as the European Federation of Crohn’s and Ulcerative Colitis Associations it will be fascinating to view the development of nurses’ roles increase and advance within this speciality.

10. Limitations

There are limitations to this study, mainly due to selection bias. This survey included only nurses who attended N-ECCO School and N-ECCO Network Meeting in 2012 and was not representative of the wider IBD nursing community. Nevertheless, this survey has provided a decent understanding of the current nursing roles in caring for patient with IBD across Europe.

A criticism of this survey tool is that it has not been possible to identify the particular group of nurses across each of the countries who are not undertaking such independent roles. The authors concur that it is possible that some of the nurses who completed this survey may not need to independently advise nor assess patients as part of their current role, and within the survey it was not possible to identify this group. Additionally, the survey did not request nurses to define themselves according to an advanced nursing role or nurse working in any setting, which would have allowed for clearer role definition and correlation with role responsibility. Furthermore, the survey did not request for nurses to define if their role was within the medical or surgical field.

11. Conclusion

This survey has provided an understanding of the nursing role in the care of patients with IBD across Europe including Australia, Canada and Israel. This survey demonstrates that the role of nurses in IBD exists in various settings within hospital care, providing complex management and autonomous nursing care in a range of services to a significant number of patients with IBD.

It is possible for this to be corrected for further surveys which would be beneficial to identify the actual level of clinical responsibility and education level of the nurses with country comparisons.

Conflict of interest

None.
# Acknowledgements/collaborators

A. Dignass, L. Younge and P. Détré were involved in the development of the content of the survey instrument. Julie Duncan (UK N-ECCO National Representative, 2013–2015) provided independent review and suggestion to the lead author of this paper. Alison de Lima and Veerle Nuij — PhD students at the Department of Gastroenterology and Hepatology, Erasmus MC, Rotterdam, Netherlands, provided the statistical analysis of the data. N-ECCO National Reps (2011–2012) for being involved in the pilot phase of trialling the survey.

# Appendix A

**A SURVEY OF IBD NURSING PRACTICE TO GAIN AN UNDERSTANDING OF THE NURSING ROLE IN CARING FOR PATIENTS WITH CROHN'S DISEASE & ULCERATIVE COLITIS IN EUROPE**

The role of an IBD nurse is predominantly to care for patients suffering from Crohn's disease and Ulcerative Colitis. The service that an IBD nurse provides can vary widely from hospital to hospital, and country to country and this can particularly depend on the local requirements of the patients and the gastroenterology team. N-ECCO was created to provide opportunities for IBD nurses throughout Europe to meet and share best practice, with the hope of enhancing the care that all of our IBD patients receive, wherever they live.

**PLEASE NOTE THAT YOUR ANSWERS SHOULD REFLECT YOUR CURRENT PRACTICE & TRAINING. ANSWERS WILL REMAIN CONFIDENTIAL BUT WE KINDLY ASK YOU TO TICK THE APPROPRIATE BOX BELOW. KINDLY ALSO COMPLETE THE BACK PAGE.**

(Demographics)

1. I am
   - Adult IBD nurse
   - Paediatric IBD nurse
   - Research nurse
   - Gastroenterology nurse who also cares for IBD patients
   - Other

Please tick more than one of the above if appropriate and explain below

Education

4. I have completed the following level of nursing training
   (Please tick one only which reflects your highest level of current training)
   - Certificate
   - Degree
   - Diploma
   - Masters
   - Other – please specify

5. Is there access for nurses in your country to any specific IBD nursing education in your country?
   (If so please specify what it & at which level certificate, diploma, degree or Masters level)

Profession

6. I work in the following type of centre
   - Academic centre
   - A public hospital
   - A private hospital
   - Other - please specify

7. How long have you been working in this role?
   - <1 year
   - 1–5 years
   - 6–10 years
   - >10 years

8. On average, I see xx IBD patients per week?
   - <5 patients
   - 5–15 patients
   - 16–25 patients
   - 26–35 patients
   - 36–45 patients
   - >45 patients
References

1. Royal College of Physicians. UK IBD Audit 3rd round: national results for the organisation of adult inflammatory bowel disease services in the UK. Royal College of Physicians; 2010.


