



CENTRE FOR LEADERSHIP AND PRACTICE INNOVATION

A SYSTEMATIC REVIEW OF THE EFFECTIVENESS OF
INFLAMMATORY BOWEL DISEASE SPECIALIST NURSES

EXECUTIVE SUMMARY

RESEARCH TEAM

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EXECUTIVE SUMMARY

Project aims and objectives

The National Association for Colitis and Crohn's Disease (NACC) commissioned this systematic review of the literature with the aims of defining the scope of specialist IBD nursing roles, and examining the evidence relating to their perceived value, benefits and effectiveness.

Study design

A systematic review, involving comprehensive searches of both the published and unpublished literature was conducted. Inclusion criteria for studies to be assessed as part of the review were developed and agreed by the research team and sponsors.

- For inclusion, studies needed to evaluate nurse-led interventions or services to patients diagnosed with IBD.
- A range of physical and psycho-social outcome measures to assess effectiveness and value of IBD specialist nurses were identified and agreed.
- Retrieved literature was restricted to the English language and publication between January 1995 and February 2006.
- Grey literature, including information of ongoing research, local audit data and reports, along with an analysis of nominations for the NACC Nursing Award 2005, were used to supplement the published literature.

Results of the search

Initial implementation of the search strategy yielded a total of 5099 potential citations across all databases. Due to the breadth of the search terms and some cataloguing anomalies on various databases, the vast majority of the 5099 initial citations were excluded from the review.

- A total of 91 references were reviewed in full independently, by two reviewers. At this stage they were either: rejected; met the inclusion criteria; or thirdly, failed to meet the inclusion criteria for the IBD specialist nursing section, but were related to the general context of the review and retained.

Analysis

The methodological quality of the research papers was evaluated independently by two reviewers in accordance with guidelines and principles of the Cochrane Collaboration for Systematic Reviews. In addition to published research on the scope of specialist IBD and gastroenterology nursing roles, a variety of non-research literature describing role specifications and models, professional body guidelines and training programmes were incorporated into the review for contextual purposes.

Results

The roles and competencies of nurses undertaking endoscopy / sigmoidoscopy / colonoscopy

A significant amount of literature was identified relating the roles and competencies of nurses undertaking endoscopy / sigmoidoscopy / colonoscopy. Whilst many of these papers did not make specific mention of IBD they were nonetheless included in the review at the request of the expert panel and study sponsors.

- Twenty-nine studies met the inclusion criteria for the review.
- After independent quality assessments by two reviewers, 4 studies scored as high quality, 9 as moderate quality and 16 as low quality.
- The studies provided sufficient evidence to suggest that, given adequate training, nurses are at least as safe, accurate and reliable as medical staff in performing the highly specialised technical procedures involved in endoscopy and flexible sigmoidoscopy.
- Nurses trained in endoscopy and flexible sigmoidoscopy are capable of accurately diagnosing IBD and other gastrointestinal conditions, independently of a supervising physician.
- There is little or no literature reporting an integrated role of the IBD nurse specialist who undertakes endoscopies as just one part of her clinical duties.

Studies evaluating the impact of nurse-led IBD services

Three published studies met criteria for inclusion in this report, two evaluating the impact of a nurse-led service in the management of patients with inflammatory bowel disease and one evaluating the impact of a nurse-led counselling service on quality of life in patients with inflammatory bowel disease. Two papers describing small surveys associated with the acceptance and establishment of IBD specialist nursing posts were also identified.

- The literature overwhelmingly reports positive findings in relation to the IBD nursing role.
- Benefits identified include: increased access for patients to specialist IBD nurses via telephone helplines and nurse-led clinics, especially at times of disease exacerbation; the ability of specialist nurses to appropriately assess, investigate, modify treatment, monitor and review IBD patients via treatment guidelines; provision of emotional and physical support; increased patient satisfaction in a variety of areas including nurse-led management of disease, patient education and advice, and facilitation of self-help practices; reduction in outpatient attendances and waiting times; and short-term effectiveness of specialist IBD nurse counselling intervention.
- Patients and GPs are in favour of the development of IBD specialist nursing roles.

Limitations

The methodological rigour of the published literature reviewed needs to be considered when reviewing these results. The diverse nature of the studies, varying sample sizes, and a lack of detail in terms of recruitment, reliability and study design, mean that any generalisations of the findings must be viewed with caution.

Grey literature

The search of the grey literature resulted in the identification of one ongoing trial and one unreported randomised control trial. A request for additional information about IBD specialist nursing roles was made via NACC and the RCN Gastroenterology and Stoma Care Nursing Forum. This resulted in over a dozen nurses contacting the review team offering a range of useful information including audits, clinical guidelines, presentation summaries, job descriptions and local reports. Data from eight audits were considered in detail.

- The audit data suggested that IBD specialist nurses are involved in initiating and running a variety of services for their patients including: the provision of telephone helplines; rapid and open access nurse led clinics; nurse-led outpatient IBD clinics; immunosuppression infusion and maintenance clinics; inpatient services; and involvement in a range of non-clinical activities such as education, training, research and audit.

- Some IBD nurse specialists carry substantial caseloads and often manage patients autonomously within the wider gastroenterology team.
- Patient satisfaction with IBD nurse led services is generally high.

NACC bursary nomination data

In 2005 NACC members were invited to nominate specialist nurses for the NACC Nursing Award. 131 anonymised nominations from patients, doctors, relatives and carers were subject to analysis as part of the grey literature.

- The data identifies a number of positive attributes of nurses who care for patients with IBD.
- What is evident from the analysis is that technical competence in procedures is hardly, if ever mentioned.
- Whilst the importance of the in-depth knowledge of specialist nurses and their ability to help patients manage their disease, whether routinely or at times of flare up is acknowledged, it is the traditional nursing values and qualities such as empathy, support, continuity and closeness of contact, communication, time, individualism, advocacy and holism that patients frequently mention as important.

Concluding summary of the findings

The evidence provided in this report illustrates a number of cases where nurses have successfully developed their roles and skills in the care and management of patients with IBD and in gastroenterology nursing in general. The literature however reflects considerable variation in the extent and scope of specialist nursing roles in gastroenterology.

- Evidence from both the published literature and local audits appear to demonstrate that nurses are instrumental in developing new services which enable patients to have easier and / or better access to health care professionals. Examples include: establishing telephone helplines; the provision of open and rapid access clinics as well as other nurse-led IBD outpatient clinics; establishing immunosuppression infusion and maintenance clinics; delivering inpatient services; and involvement in a range of non-clinical activities such as education, training, research and audit. Once again however, evidence is primarily limited to audit data and as such is of questionable quality.
- Patient satisfaction with the standard and scope of nursing care delivery is generally reported as high.
- Explicit models of IBD specialist nursing practice are largely absent in the published literature and at best have to be inferred from the grey literature at this time.

The data analysed from the NACC Bursary Award nominations would suggest that IBD patients are often managed by generic gastroenterology teams and nurses, as only 30% of the 131 nominations identify IBD specialist nurses. In addition, there is no evidence of specialist IBD nursing roles being based or operating in Primary Care contexts. Therefore, it can be concluded that models of clinical practice, as outlined in the literature and audit data, are likely to be determined by local provision, the availability of specialist nurses, and service need.

Recommendations for further research

It is clear from the review that there are a number of areas where further research into the role and effectiveness of IBD specialist nurses is needed. The following areas are suggested for consideration:

- There is a need to identify a common set of skills, knowledge and competencies required of IBD specialist nurses
- Identification of the educational preparation requirements for IBD specialist nurses and their ongoing training and development needs
- A scoping exercise is recommended to identify the number of IBD specialist nurses currently in post, their scope and model of practice, and the contexts in which they operate
- Prospective, rigorously designed studies, exploring the clinical and cost effectiveness of IBD specialist nursing roles would be helpful in identifying the value and benefits that IBD specialist nurses bring to this patient population and service organisations.