

# Inflammatory bowel disease management: a review of nurses' roles in Australia and the United Kingdom

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## KEY WORDS

inflammatory bowel, nurse, Crohn's disease, ulcerative  
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## ABSTRACT

### Objective

To explore the role of Australian nurses in the provision  
of inflammatory bowel disease (IBD) health services.

### Design

A questionnaire survey.

### Setting

Hospitals in Australia and the South West of the United  
Kingdom (UK).

### Subjects

Inflammatory bowel disease nurses.

### Main outcome measure

The diversity of IBD services.

### Results

Twelve Australian and 19 UK nurses returned  
completed questionnaires (approximately 40%  
response rate). Most participants were registered  
nurses, aged between 25 and 55 years. More UK  
participants were IBD specialist nurses (84% vs 42%;  
 $p = 0.019$ ) and the majority of Australian nurses  
being clinical trial coordinators. The UK nurses had  
more interest in IBD (100% vs 75%;  $p = 0.049$ ) and  
spent more time in IBD nursing (63% vs 25%;  $p =$   
0.043). Nurses in the UK provided more IBD services  
and tended to perceive a higher level of support from  
management (52% vs 25%;  $p = 0.12$ ). Fewer IBD  
services were provided by Australian nurses despite  
their equivalent educational attainments, years of  
IBD experience and level of autonomous practice.  
Australian nurses identified the lack of funding,  
time and management support as barrier to service  
development. Australian nurses were less likely to be  
employed as dedicated IBD nurses and were required  
to provide nursing services to a wider clientele.

### Conclusion

In this study Australian IBD nurses had less specialised  
roles, attracted less funding and management support.  
Australian nurses were more focussed on clinical trial  
coordination and provided for a wider clientele.

## INTRODUCTION

This study examined the role of inflammatory bowel disease nurses in Australia and the United Kingdom.

### Background

Inflammatory bowel disease encompasses Crohn's disease (CD) and ulcerative colitis (UC). These are conditions where the intestinal mucosa becomes inflamed with no apparent cause. Symptoms of inflammation are increased bowel frequency, diarrhoea, faecal urgency resulting in incontinence, passage of blood per rectum, loss of appetite, anaemia, fatigue, abdominal pain and tenderness (Jewel et al 2001). Some patients may also experience extra intestinal complications involving inflammation in the biliary tract, skin, mouth, eyes and joints (Jewell et al 2001).

Inflammatory bowel disease is a chronic relapsing and remitting condition that can cause high morbidity and a reduction in health related quality of life. People of all ages can develop IBD, but commonly young people are affected. Inflammatory bowel disease therefore impacts on the formative years of life throughout childhood and young adulthood. People with IBD report a greater disease burden than other common digestive disorders and have fewer employment prospects when the disease is active (Calsbeek et al 2006). The impact of IBD affects family members to varying degrees. The risk of developing colorectal cancer increases in patients who have extensive IBD for long periods of time. Other complications such as malnutrition, growth failure (in children and adolescents) and osteoporosis are also common.

Because of the morbidity and chronicity of IBD and the potential for complications, long term medical follow up and other multi-disciplinary input would be warranted (Gibson and Iser 2005). Having a multi-professional approach to care delivery could improve the holistic approach and increase the diversity of services. Addition of a specialist nurse might further improve the appropriateness of self-management and the access to specialist services by providing on-going education and a point

of contact during disease relapse (Mawdsley et al 2006). Nurses are able to provide additional support and services targeting quality of life issues including how to cope with urgency and incontinence which are common in acute episodes of IBD. (Mason 2007)

### Literature Review

The concept of IBD nursing was not new in some countries such as England and Wales (Phillips 1995). In the early 1990s, a number of nurses independently developed their roles to include supporting patients with IBD (S. Phillips, personal communication, May 5, 2001). The nurses' role in IBD has been evaluated in several hospitals, and a reduction in the number of hospital stays, outpatient attendance and an improvement in quality of life measurements have been reported (Nightingale et al 2000). Fifteen years on, the role of the IBD nurse is well established in many hospitals in the UK (Roberts 2007; Murphy 2006). The IBD nursing role had been endorsed by the British Society of Gastroenterology (Carter et al 2004) and the National Association of Crohn's and Colitis (Birmingham 2005). Recognised qualification was available for nurses who wished to specialise in this area to enhance understanding of the needs of this patient group (Burdett Institute of Gastrointestinal Nursing, n.d.)

In Australia, the role of IBD nurse is a new concept. Only two nurses were known to hold official funded positions in this field in 2007 (S. Buckton, personal communication, September 30, 2007; S. Mason, personal communication, March 31, 2007). A number of nurses provided some support and services to people with IBD within other positions (J. Philpot, personal communication, October 23, 2007; B. Headon, personal communication, January 10, 2006; Reid 2005; Leach et al 2005). Types of services offered include telephone support, blood test monitoring, new patient education and teaching self injections.

In the context of different systems of health care structure, the role of an IBD nurse in Australia might differ from their UK counterparts. The IBD patient group is expected to be a high consumer of

outpatient and inpatient health services throughout the patients' lifetime (Access Economics Pty Limited 2007). Evaluation of health service delivery to this client group was, therefore, valuable both in terms of health economic calculation and quality improvement in service provision.

To date there had been no study examining nurses' role in the field of IBD in Australia. It was unclear whether nurses contributed to providing specialist services to this client group. Nurses had an interest in IBD and had the desire to input nursing expertise in this field, as evidenced by the formation of the Australian IBD nurses' network group (Reid 2007).

### **Current study**

The primary aim of this study was to increase understanding of the status of the Australian IBD nursing role. This survey was designed to identify the attributes of Australian IBD nurses, their current job roles and their work settings.

The secondary aim was to identify important characteristics that had an impact on service development. The same survey was conducted in a group of established IBD nurses in the UK as a comparison. Results would provide useful insight for health service developers, consumers, education providers and other IBD interest groups. In addition topics for future research could be identified.

### **METHODOLOGY**

This is a pilot study. The study utilised a questionnaire to elicit information from IBD nurses. A validated questionnaire was unable to be sourced. The researchers had, therefore, developed the questionnaire used in the study. Internal validation was obtained by trialling the questionnaire on one potential Australian participant and one potential British participant, whose suggestions were incorporated into the final version. Inflammatory bowel disease nurses in the study worked in health facilities across Australia and the UK.

The final questionnaire consisted of 20 questions. It was constructed to be e-mailed out to each potential participant. Questions one to six gathered

information on demographics, nursing qualifications, educational attainment and IBD experience. Questions seven to fifteen evaluated nurses' current job roles, client groups, service provision to IBD patients, interest in IBD, level of perceived support, professional status and barriers to providing IBD services. Questions sixteen to twenty evaluated information on the work setting. Throughout the questionnaire nurses were invited to provide additional free text comments.

Participants were recruited from invitations sent out to nurses on the contact lists for Australian IBD and the UK South-west IBD nurses. In addition, informal invitations also took place between potential participants and their colleagues.

### **STATISTICAL ANALYSIS**

Descriptive data were obtained and displayed. Fisher's exact test was used to calculate statistical significance. Fisher's exact test was considered an appropriate test to use as the study consisted of a small number of participants and involved the comparison of two groups.

### **FINDINGS**

Twelve Australian and 19 UK nurses responded. The response rates were 31% and 54%, respectively.

#### **Experience and qualifications**

Nurses were predominantly registered division one nurses in both countries (Australian group = 92%; UK group = 100%). The majority of participants had experience in IBD for 4 or more years (75% in the Australian group and 79% in the UK group). Some had over 10 years of IBD experience (42% in the Australian group and 21% in the UK group).

Nurses' academic achievements varied. More Australian nurses achieved a hospital certificate (33% versus 11%) or a Master degree (42% versus 26%). More UK nurses had a Bachelor degree (26% versus 8%) or a post-graduate diploma (26% versus 8%), and had an IBD-specific qualification (42% of the UK participants versus 8% of the Australian participants). However, all these differences did not reach statistical significance.

## Demographics

All participants were women and aged 25 years or above. Most of the UK participants indicated they were in the 25-40 years age range (53%). Most of the Australian nurses indicated they were in the 41-55 years age range (67%). Australian participants came from New South Wales, Victoria, South Australia, Western Australia, Queensland and the Australian

Capital Territory. No participants came from the Northern Territory or Tasmania in this study. The UK participants were from the south west of the UK.

## Job Descriptions

Inflammatory bowel disease nurses filled a wide range of roles. As shown in table 1, UK nurses were more likely to be 'IBD specialist nurses' and Australian nurses 'clinical trial research nurses'.

**Table 1: Nurses' roles**

|                      | Endoscopy or<br>Day Procedure<br>Unit nurse | Clinical trial<br>research nurse | General Gastro<br>Clinic nurse | Specialist IBD<br>clinic nurse | IBD specialist<br>nurse | Other   |
|----------------------|---|----------------------------------|--------------------------------|--------------------------------|-------------------------|---------|
| Australia (N=12)     | 0   | 7 (58%)                          | 1 (8%)                         | 4 (33%)                        | 5 (42%)                 | 5 (42%) |
| UK (N=19)            | 2 (11%)                                     | 1 (5%)                           | 0                              | 6 (32%)                        | 16 (84%)                | 7 (37%) |
| P-value <sup>a</sup> | ns  | 0.002                            | ns                             | ns                             | 0.02                    | ns      |

<sup>a</sup> Fisher's exact test

ns Not significant

## Provision of IBD services

As outlined in table 2, all British nurses were operating a telephone support line, and providing IBD education, coordination of IBD treatment, face-to-face nurse-led clinics, and writing guidelines and protocols for IBD. More British nurses engaged in general ward

nursing, IBD treatment monitoring, telephone clinics, prescribing, ordering tests, nurse endoscopy (as a nurse practitioner), and smoking cessation support. A smaller proportion of Australian IBD nurses were providing similar services.

**Table 2: Provision of IBD services**

|  | Australia (n=12) | UK (n=19) | P-value |
|--|------------------|-----------|---------|
| Telephone support line                   | 9 (75%)          | 19 (100%) | 0.05    |
| IBD education                            | 11 (92%)         | 19 (100%) | 0.39    |
| IBD treatment coordination               | 10 (83%)         | 19 (100%) | 0.14    |
| Nurse-led clinics                        | 3 (25%)          | 19 (100%) | 0.00001 |
| Writing guidelines and protocols for IBD | 5 (42%)          | 19 (100%) | 0.0003  |
| General Ward nursing                     | 4 (33%)          | 12 (63%)  | 0.15    |
| IBD treatment monitoring                 | 8 (67%)          | 18 (95%)  | 0.06    |
| Telephone clinics                        | 2 (17%)          | 10 (53%)  | 0.07    |
| Prescribing                              | 1 (8%)           | 10 (53%)  | 0.02    |
| Ordering tests                           | 6 (50%)          | 18 (95%)  | 0.007   |
| Nurse endoscopy as (NP)                  | 0                | 8 (42%)   | 0.01    |
| Smoking cessation support                | 1 (8%)           | 11 (58%)  | 0.008   |

**Table 3: Other client groups**

|                           | Australia (n=12) | UK (n=19) | P-value |
|---------------------------|------------------|-----------|---------|
| None (i.e. dedicated IBD) | 1 (8%)           | 9 (47%)   | 0.05    |
| Coeliac disease           | 4 (33%)          | 3 (16%)   | 0.38    |
| General gastro            | 7 (58%)          | 6 (32%)   | 0.26    |
| General surgical          | 1 (8%)           | 0         | 0.38    |
| General medical           | 2 (17%)          | 1 (5%)    | 0.54    |
| Functional gut disorders  | 2 (17%)          | 3 (16%)   | 1       |
| Colorectal                | 1 (8%)           | 2 (11%)   | 1       |
| General outpatients       | 1 (8%)           | 2 (11%)   | 1       |
| General endoscopy         | 0                | 1 (5%)    | 1       |
| Other                     | 5 (42%)          | 3 (16%)   | 0.21    |

More United Kingdom nurses were providing dedicated services for IBD patients (47% versus 8%,  $p = 0.05$ ). Australian nurses were providing services for a wider range of conditions (table 3).

### Nurses' interest in IBD

All nurses expressed an interest in providing services for IBD patients. However, more enthusiasm

was shown among the United Kingdom nurses (100% vs 75%,  $p = 0.05$ ).

### Perceived Support for IBD role development

There was more perceived support from senior nursing managers and senior medical staff in the United Kingdom group, as outlined in table 4.

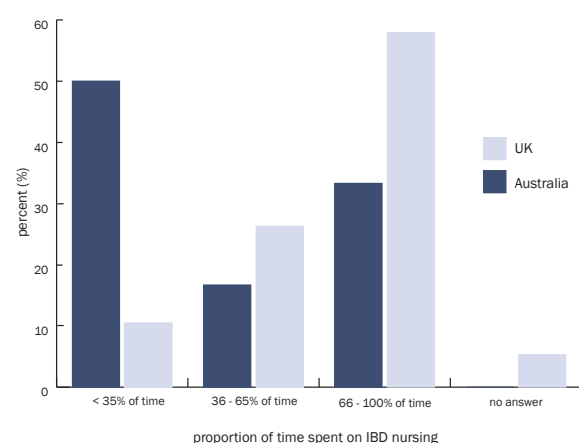
**Table 4: Senior management support for developing IBD services**

| Senior nursing support available | Australia | UK  | Senior medical support   | Australia | UK  |
|----------------------------------|-----------|-----|--------------------------|-----------|-----|
| <b>Strongly agree</b>            | 0%        | 26% | <b>Strongly agree</b>    | 42%       | 79% |
| <b>Agree</b>                     | 50%       | 68% | <b>Agree</b>             | 50%       | 16% |
| <b>Disagree</b>                  | 42%       | 5%  | <b>Disagree</b>          | 8%        | 5%  |
| <b>Strongly disagree</b>         | 8%        | 0%  | <b>Strongly disagree</b> | 0%        | 0%  |

### Other Role Characteristics

Nurses were asked whether autonomy, advanced practice, reporting directly to gastroenterologists and GPs, providing education for fellow nurses, and involvement in conference presentation were features of their job roles. The majority of the Australian and UK nurses were reporting directly to their senior medical colleagues. About one third of nurses in both groups had involvement in conference presentation. However, UK nurses tended to have more autonomy (63% vs 33%,  $p = 0.11$ ), and more frequently to exercise advanced practice (47% vs 25%,  $p = 0.19$ ) and to provide education to fellow nurses (42% vs 25%,  $p = 0.28$ ), although these differences were not statistically significant.

**Figure 1: Time spent in IBD nursing**



As shown in figure 1, Australian nurses spent less time in IBD-specific nursing than their UK counterparts. These answers were in agreement with other answers where 47% of UK participants exclusively provided services to IBD patients. Having time was a factor thought to impact on IBD service provision.

### Potential Services

Nurses were asked if they felt additional services should be provided for people with IBD and what these should be. The most popular IBD services that Australian nurses wished to offer were operating telephone support line (50%); paediatric transition care (50%); cigarette smoking cessation support (50%); and nurse clinics (45%).

Two of these services (operating telephone support line and nurse clinics) were already being provided by all of the UK IBD nurses in the study.

### Reasons for not providing IBD services

Australian nurses did not provide IBD services because they were 'not part of [their] job description' (58% versus 11%,  $p = 0.01$ , statistically significant). Australian nurses had less 'nursing management support' (50% versus 16%,  $p = 0.05$ , statistically significant). Australian nurses also more frequently cited 'insufficient time' (75% vs 50%,  $P = 0.19$ ), 'lack of medical support' (25% vs 0%,  $p = 0.05$ , statistically significant) and 'lack of funds and budget allocation' (83% vs 42%,  $p = 0.03$ , statistically significant) as



reasons for not providing additional services. 'lack of knowledge or expertise' and 'inadequate facilities' was cited equally by nurses in both countries (33% of Australian and 26% of UK nurses,  $p = 0.80$ ).

### Work Place Characteristics

The majority of nurses worked in a public facility (92% Australian vs 84% UK). More Australian nurses worked in a tertiary health facility (75% vs 11%) and more UK nurses worked in a secondary health facility (79% vs 8%). The remainder of the respondents worked in a primary health facility (17% Australian vs 11% UK). In addition clinical trials were more likely to be conducted in tertiary centres.

Nurses from both groups described similar characteristics in the patient population they served. Nurses served a mainly urban patient population or a mixture of urban and rural patient population. Australian nurses in the study had a tendency to work with more gastroenterologists and in smaller facilities (100–300 beds). UK nurses tended to work with fewer gastroenterologists and in larger facilities (>500 beds).

## DISCUSSION

Being a pilot study, study results should not be extrapolated to the whole target population. However, the results do provide insights into differences and similarities between conditions, attitudes and expectations of IBD nurses in the UK and in Australia.

The higher percentage of older Australian nurses might explain why more Australian nurses had hospital certificates as their highest qualification. Prior to the 1990s the majority of nurses were trained within the hospital system achieving a hospital certificate. After this time nurses' training became increasingly based in the university system. At the completion of training the result was the acquisition of a Bachelor degree. (Russell 1988.)

British IBD nurses surveyed were frequently providing a wider diversity of IBD services. This is not unexpected as IBD nursing has progressed rapidly in the UK in the past fifteen years and the role

of an IBD nurse has been accepted amongst gastroenterologists, IBD patients and health service providers (Roberts 2007; Murphy 2006).

### Nursing Expertise Under-utilised in Australia

Australian nurses may be under-utilised in terms of their skills and experience when compared with their counterparts in the UK where nurses are an integral part of a multi-professional team especially in chronic disease management. In Australia, the specialist nurses role development is evident but has been slower. Some of the barriers to maximising nurses' input in other disciplines have been identified as relating to funding, regulatory and inter-professional issues (Halcomb et al 2008). Nurses who are entrepreneurial sometimes lack the authority to effect changes successfully. They are dependent on cultivating relationships with more powerful others in order to develop new services and implement new ideas. In this study more Australian nurses reported inadequate support from senior nursing personnel.

### Evidence of Effectiveness

It is difficult to measure the value of a nursing role. Benefits to patient outcome are likely to be in the form of their perception of increased support. However one study has shown that specialist nurses were effective in monitoring IBD treatments (Holbrook 2007.) Patients do not necessarily consider increased technical skills as the most valuable in their specialist nurse. Instead patients may perceive support, advice, caring, empathy and disease management to be of particular importance to their care (Belling et al 2008).

Inflammatory bowel disease service delivery can be made more efficient and more demand-directed. This is being implemented and evaluated in several countries in Europe including Sweden where service redesign included a direct telephone line, appointment schedule according to expected needs, acute appointments being available daily, traditional follow up replaced by yearly telephone follow up and the registration of any ward utilisation (Rejler et al 2007). The development of nurse-led services such as patient education, pain management and support

for quality of life issues is also evident in the USA (Dettinger et al 2008; Ruthruff 2007). There may be potential to re-organise IBD management to improve efficacy. Direct comparison of alternative modes of service delivery including nurse-led treatment monitoring, treatment coordination and primary care involvement may be required (Altschuler et al 2008).

### **IBD Health Expenditure in Australia**

Health expenditures on IBD are high and were conservatively estimated as \$68 million in 2005, as shown in a recent Australian economic evaluation commissioned by the Australian Crohn's and Colitis Association (Access Economics Pty Limited 2007). The total financial costs of IBD in 2005 were estimated to be near \$500 million. This cost included health expenditures and productivity losses. It had been observed that IBD patients in Australia frequently utilised more than one gastroenterologist's services (B. Headon, personal communication, January 30, 2007). This would result in service overlap, fragmentation of care and a high consumption in Medicare claims and private health care.

### **Funding for IBD nursing in Australia**

In this study, more UK participants were 'IBD specialist nurses' and more Australian participants were 'clinical trial coordinators'. This may be an indication there was a lack of dedicated funding source in Australia. The higher proportion of clinical trial coordinators in Australia correlated to the higher percentage working in tertiary referral centres. Nursing involvement with IBD patients may be more prevalent in tertiary sectors in Australia. The opportunity for additional support for IBD patients was gained through funding from conducting clinical trials. A clear funding source and a dedicated job description may be related to more IBD service provision.

A higher IBD interest was associated with more IBD services being provided. Nurses employed specifically as 'IBD nurses' were likely to feel more positive, interested and were more inclined to provide IBD services. Having time was an important determinant

in the provision of services. It is difficult to provide additional services when other job responsibilities are demanding as is the case with clinical trial coordination. Australian IBD nurses perceived a lack of funding and dedicated time as barriers to service provision.

At present, nursing services do not attract Federal Government funding in Australia. Even in the case of nurse practitioners where they provide services equivalent to general practitioners, they are not eligible to be given a Medicare provider number. As a result, the costs of nursing services are not recoverable from the funding stream designed to support such services (Nurse Practitioner – Like Services in Residential Aged Care Services, 2008).

### **The future of IBD nursing in Australia**

People with IBD have a normal or near normal life expectancy (Andrews and Goulston 1994). Inflammatory bowel disease nursing will become increasingly important due to an aging population. Secure government funding is essential for the future of IBD nursing development. Since the Federal Government takes most responsibility for ambulatory care, such funding would be best in the form of Federal specific development grants or Medicare reimbursement. Provider status is an important element in order to recognise and sustain a health care profession. Health service providers either choose to subsidise non-reimbursable activities or choose not to provide these services. In addition services that are not reimbursed through the private system tend not to be provided.

### **LIMITATION**

Study participants were members of IBD interest groups and provided a convenient sample. Results therefore belong to a selective group and may not apply to the rest of the target population. The lack of a definition for an IBD nurse, an emerging new role and the small number involved in the study made it difficult to perform a direct comparison between the two countries. Participants included specialist nurses and clinical nurses whose roles are inherently different. Opinions from other stakeholders such

as clinicians, patients and decision makers within health services would be relevant. These are beyond the scope of this study.

## CONCLUSION

The study demonstrated that IBD nurses were providing less IBD specific services in Australia, compared to nurses in the UK. Factors preventing service development have been cited to include a lack of senior medical and nursing support, insufficient funding and a low emphasis of the IBD nursing role within nurses' job descriptions. There is potential to improve the provision of IBD services and reduce health related expenditure in IBD by increased utilisation of IBD nurses in Australia, through Medicare funding.

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