

Title: Living more effectively with fatigue in Inflammatory Bowel Disease.

Introduction: Inflammatory Bowel Disease (IBD) affects 240,000 people in the UK. Fatigue is reported as the most troublesome symptom when IBD is in remission; more than 40% report this symptom. It is demoralising and impacts on all aspects of daily life. Fatigue is common across a range of other chronic health care diagnoses, where it has also been demonstrated to exert a detrimental effect on quality of life. However there has been little attention given to the nature and extent of problems caused by fatigue in IBD and no intervention studies to date. There is a need to identify the best way to assess IBD fatigue, to establish what patients feel they need and to develop and test interventions based on patient needs and evidence from other chronic illnesses, aiming to improve symptoms and quality of life.

Aims: 1. Identify a fatigue measurement instrument which best reflects the experience and concerns of patients with IBD fatigue. 2. Develop and evaluate a fatigue management programme for IBD.

The hypotheses to be tested are: 1. One of the three most widely used chronic fatigue assessment scales can adequately reflect the experience and concerns of people self-identifying as experiencing IBD fatigue. 2. Face to face delivery of a fatigue management programme improves IBD fatigue as well as an internet-based programme. 3. Both programmes significantly improve fatigue compared to baseline levels. 4. Any benefit is maintained for at least 12 months after the end of the intervention.

Plan of Investigation: I will administer 3 validated fatigue measurement tools to people with chronic IBD-related fatigue and conduct in-depth qualitative interviews to explore which of these tools has the “best fit” for their experience and concerns. The interviews will also identify coping mechanisms and views on what sort of intervention is needed. The interviews will be transcribed verbatim and analysed thematically. Recruitment will continue until data saturation is reached (anticipated 15-20 interviews). Based on the above results and what is known to work in other diseases associated with chronic fatigue, I will develop and pilot two intervention approaches with 40 patients (20 in each arm), in a partially-randomised preference design study, evaluated using the identified instrument at 3, 6 and 12 months.

Potential Impact: Publication of the results from this study in the medical and patient press will lead to recognition of IBD fatigue amongst health professionals and patients as a legitimate issue for discussion. It has the potential to lead to earlier diagnosis and management of this common problem, improving daily functioning of people with IBD and quality of life (QoL). Identification of the best fatigue measurement scale will enable case finding and evaluation of interventions. Development and pilot evaluation of an IBD fatigue management programme for use by patients and IBD specialist nurses, which could be rolled out across the UK, has the potential to improve symptoms and QoL.

I would like to attend the RCN Annual International Nursing Research Conference because I would like to be at the heart of where new research will be presented, critically analysed and to take my own conclusions back to my professional practice.

Nursing is a very vibrant and wide ranging profession. Nurses come across many challenges in terms of their knowledge and skills and if they are to provide a high quality, up-to-date, efficient and effective patient care they need to develop their knowledge and keep it up-to-date. Through working together, sharing knowledge, and acting as critical reviewers for each other in terms of promoting good practice we can find new solutions. Attending this conference would provide me with the chance of listening to presentations by many specialists and leading experts in clinical, educational and methodological research. It would also open the platform for me to establish collaboration and networking with national and international experts in the area of my own research.

Having just recently registered for a part-time PhD, attending the conference will give me a unique opportunity to listen to the first-hand experience of other researchers and to learn from them about the practical aspect of conducting research and problem solving. I would also like to present my own research data in the area of inflammatory bowel disease and related fatigue. This is a preliminary qualitative study looking at patients' experience and ways of managing fatigue. I would like to receive constructive comments and suggestions to help me shape my research project, as there is very little published information currently available, to the benefit of this under researched group of people.