Disease management and patient satisfaction in inflammatory bowel disease

A randomised controlled trial to assess the impact of a package comprising a patient-orientated, evidence-based self-help guidebook and patient-centred consultations on disease management and satisfaction in inflammatory bowel disease

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Executive summary

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Executive summary

Objectives

The aim of this study was to determine if a whole systems approach to self-management using a guidebook developed with patients combined with physicians trained in patient-centred care improves clinical outcomes and leads to cost-effective use of NHS services.

Design

The design was a pragmatic cluster trial with randomisation by treatment centre. Nineteen hospitals were randomised to 10 control sites and nine intervention sites. Consultants from intervention sites received training in patient-centred care before recruitment and introduced the intervention to eligible patients. Patients at the control sites were recruited and went on to have an ordinary consultation. Qualitative interviews were undertaken to obtain an in-depth understanding of patients' and consultants' experience of the intervention.

Setting

The study was conducted in follow-up outpatient clinics at 19 hospitals in the north-west of England.

Subjects

A total of 700 patients (297 at intervention sites and 403 at control sites) were recruited who had established ulcerative colitis or Crohn's disease, were aged 16 years and over and able to write in English.

Interventions

The intervention included the following components:

- training consultants to provide a patient-centred approach to care
- provision to patients of an information guidebook; guidebooks on ulcerative colitis and Crohn's disease were developed with patients prior to the study
- negotiation of a written self-management plan
- improving access to services – patients to self-refer to services based on a self-evaluation of their need for advice.

Main outcome measures

The main outcomes measured were the rates of hospital outpatient consultation, quality of life and acceptability to patients. Other clinical outcomes included anxiety and depression, patient enablement, patient satisfaction, relapse duration and the interval between relapse and treatment. The economic evaluation looked at health service resource use and assessed cost effectiveness using the EQ-5D. Data were obtained at baseline through face-to-face interviews and at 12 months from patient diaries, postal questionnaires and hospital medical records. Processes underlying outcomes were the focus of the qualitative interviews.

Results

After 1 year, the intervention resulted in fewer hospital visits: 1.9 versus 3.0 per year ($p < 0.001$) without change in the number of primary care visits. Patients felt more able to cope with their condition ($p < 0.05$). The intervention produced no reduction in quality of life and did not raise anxiety. The intervention group reported fewer symptom relapses: 1.8 versus 2.2 ($p < 0.01$); 74% of patients in the intervention group indicated a preference to continue the system. Qualitative results showed the guidebook was effective but organisational limitations constrained patient-centred aspects of the intervention for some. Cost-effectiveness analyses favoured self-management over standard care.

Conclusions and implications

More widespread use of this method in chronic disease management seems likely to improve overall patient satisfaction and reduce health expenditure without evidence of adverse effect on

disease control. However, the qualitative data also suggest that further attention needs to be given to self-referral and access arrangements and a re-distribution of control to patients through increased adherence to patient-centred norms on the part of consultants.

Recommendations for future research

Recommendations are to evaluate the effectiveness and efficiency of operating systems within secondary and primary care which would allow self-managers to self-refer and to keep them informed of new treatments, explore models for training health professionals in methods to promote and support self-care, study long-term effects of self-management in chronic disease, transfer our approach to other chronic conditions and perform a tightly controlled study of whether faster treatment reduces the duration of relapses in inflammatory bowel disease.

Publication

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NHS R&D HTA Programme

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Initially, six HTA panels (pharmaceuticals, acute sector, primary and community care, diagnostics and imaging, population screening, methodology) helped to set the research priorities for the HTA Programme. However, during the past few years there have been a number of changes in and around NHS R&D, such as the establishment of the National Institute for Clinical Excellence (NICE) and the creation of three new research programmes: Service Delivery and Organisation (SDO); New and Emerging Applications of Technology (NEAT); and the Methodology Programme.

This has meant that the HTA panels can now focus more explicitly on health technologies ('health technologies' are broadly defined to include all interventions used to promote health, prevent and treat disease, and improve rehabilitation and long-term care) rather than settings of care. Therefore the panel structure was replaced in 2000 by three new panels: Pharmaceuticals; Therapeutic Procedures (including devices and operations); and Diagnostic Technologies and Screening.

The HTA Programme will continue to commission both primary and secondary research. The HTA Commissioning Board, supported by the National Coordinating Centre for Health Technology Assessment (NCCHTA), will consider and advise the Programme Director on the best research projects to pursue in order to address the research priorities identified by the three HTA panels.

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