Development of an Internet-Based Cohort of Patients with Inflammatory Bowel Diseases (CCFA Partners): Methodology and Initial Results

Researchers from the University of North Carolina have published the first results from CCFA Partners, an internet research project on inflammatory bowel diseases, or IBD. The goal of CCFA Partners is to help doctors and researchers get a better understanding of issues facing IBD patients, how patients are functioning and how they receive treatment. Over 7,000 people with Crohn’s disease or ulcerative colitis agreed to take the CCFA Partners internet surveys, including people from all 50 US states and other countries around the world. The surveys were completely confidential and included questions about disease, medications, daily life and activities, diet and exercise and prevention activities (like wearing sunscreen). This is what they found:

Disease type: Of the people who took the CCFA Partners surveys, 72% were women and the median age was 42 years. 63% had Crohn’s disease, 34% had ulcerative colitis and 3% had other IBD. On average, patients with Crohn’s disease had the disease for longer than patients with ulcerative colitis. The most common extraintestinal manifestation (or symptom outside of the digestive tract) was painful joints.

Medications: The most common medications used were aminosalicylates, like sulfasalazine (Azulfidine®), mesalamine (Asacol®, Pentasa®, Apriso™, Lialda®), osalazine (Dipentum®) and balsalazide. The second most common type of medications was biologics, like infliximab (Remicade®), adalimumab (Humira®) and certolizumab pegol (Cimzia®), 40% of patients with Crohn’s disease and 17% of patients with ulcerative colitis reported taking biologic medications. The third most common medications were thiopurines, like azathioprine (Imuran®, Azasan®) and 6-mercaptopurine (6-MP, Purinethol®), 25% of all patients reported taking thiopurines.

Medication Adherence: More than half of all patients got a medium to low score on medication adherence questions, which means that most patients are not taking their IBD medications correctly all of the time. In general, people felt better when they had a high medication adherence score.

Quality of Life: Patients had about the same quality of life for both Crohn’s disease and ulcerative colitis. Patients with severe ulcerative colitis had low quality of life, but quality of life returned to around average when patients had surgery to remove their colon and replace it with an internal pouch. These results show that status of inflammatory bowel disease can be an important factor in quality of life.

Prevention: Patients with IBD may be more likely to develop weak bones, infections like influenza and tuberculosis and certain cancers of the skin, cervix and colon, depending on the type of medications they use. Fortunately, there are simple activities that can prevent these from occurring. Only about half of all patients had a bone density scan or took calcium or vitamin D supplements to promote bone health. Only 40% reported having a skin exam and 16% reported always wearing sunscreen to prevent skin cancer. Less than two thirds had an influenza (flu) vaccine. These results show that not enough patients are doing simple activities to prevent weak bones, infections and cancers that may be related to IBD.

The researchers concluded that CCFA Partners is useful for studying the experiences, behaviors and outcomes of patients with IBD. They hope to follow participants in CCFA Partners over time to get a better understanding of how experiences, disease management and outcomes change over time. They also hope to use CCFA Partners to bring in other types of research, such as intervention programs or collecting biosamples for laboratory research. Information on CCFA Partners, including all of the surveys used, is available online at www.CCFAPartners.org.