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IBD EPIDEMIOLOGICAL SURVEY

In 1993 ACCAQ conducted an Inflammatory Bowel Disease Epidemiological Survey. As there have been no major changes in medical or surgical treatment of IBD since the survey was conducted, it is envisaged that the following summary of findings remains applicable today.

The survey was prepared by ACCAQ with the assistance of its medical advisers and sent to all members. Responses were recorded on a Microsoft Access Database. Over 20,000 items of data were recorded.

If you require a copy of the full 42 page report which includes copy of survey form, graphs, full statistical analyses and reasonings, please send A$10 to cover copying, postage and handling to:

ACCAQ
PO Box 497
Buddina Qld 4575

SUMMARY OF FINDINGS

This summary of findings is based on 500 replies (55% response rate) to an I.B.D. Survey distributed by ACCAQ during 1993. The full 42 page report includes tables and graphs of all data analysed together with a copy of the survey form and points to bear in mind concerning the various responses.

THE DATABASE

Of the 500 replies, 71% were female, 29% male; 66% had Crohn's disease (CD), 31% ulcerative colitis (UC) and 3% indeterminate colitis (IC). These figures cannot be assumed to reflect the national incident rates as the survey is based on patients who have contacted a support organisation of which twice as many women as men are members. It is also likely to be weighted in favour of CD as, according to requests for help received by ACCAQ, these patients generally find it harder to cope with their illness and have more complications than those with UC.

DIAGNOSIS

CHANGE IN DIAGNOSIS

25% of patients originally diagnosed with UC were later found to have CD. This finding is regarded as being very significant and of particular concern when surgery is being considered for apparent UC.

MAJOR SYMPTOMS WHICH LED PATIENT TO SEEK MEDICAL ATTENTION

58% of symptoms were gastrointestinal, 31% abdominal, 4% nutritional/hormonal. Other categories refer almost exclusively to patients with CD. Average of 2.4 symptoms per patient.

PREVIOUS INCORRECT DIAGNOSES

Most incorrect diagnoses referred to: 27% colon, 21% psychiatric, 12% infections, 10% irritable bowel syndrome (IBS). The highest number of individual responses were: 73 appendicitis, 62 psychosomatic, 27 IBS and 16 ulcer. CD had proportionately more incorrect diagnoses than UC.

DELAY IN DIAGNOSIS

Comparing the age when diagnosed with the age when symptoms first began a delay is evident, most particularly with CD. 48% were diagnosed within one year, 32% within 1-5 years, 13% between 5 and 10 years and 7% took over 10 years to be diagnosed.

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TESTS UNDERGONE TO ENABLE IBD TO BE DIAGNOSED

75% had a colonoscopy, 50% a barium x-ray. 67 (97%) of the 69 who were diagnosed by operation had CD.

WHO DIAGNOSED IBD
61% gastroenterologists, 23% surgeons, 12% general practitioners, 4% other. More surgeons and fewer GPs diagnosed CD than UC.

TIME COMPARISON

Trend suggests fewer proportionate incorrect diagnoses over last 5 years compared to 5-10 years and over 10 years ago.

AGE WHEN DIAGNOSED
34% were diagnosed when in their twenties. Youngest had symptoms when 3 months old and was diagnosed at 7 months. UC diagnosed at earlier age than CD. There is a noticeable difference in age when diagnosed between males and females, with more males than females being diagnosed before 20 years of age and between the ages of 30 and 70. Most females (38%) were diagnosed during their 20's.

AREAS OF GASTRO-INTESTINAL TRACT AFFECTED BY CD

Some patients have CD in more than one area. A total of 70% of CD patients indicated the small bowel, 62% the large bowel, 6 patients the stomach, 3 duodenum, 2 mouth and 2 oesophagus.

EXTRA-INTESTINAL PROBLEMS

63% of CD patients had symptoms outside the gastrointestinal tract, 44% of UC patients and 54% of IC. 25% had problems with joints, 16% with skin, 13% with eyes.

GENETIC AND HEREDITARY FACTORS

HEREDITARY FACTORS

19% listed a relative also with IBD. 8% listed a first line relative (father, mother. son, daughter, brother or sister).

GENETIC BACKGROUND

97% were of either European or Australian descent.

MOTHER'S AGE WHEN PATIENT WAS BORN

69% of mothers were under 30 and 31% were 30 and over

TREATMENT OF IBD

DRUGS

At any one time, patients are taking an average of 1.4 drugs for IBD. The most widely prescribed drugs were Prednisolone and Sulphasalazine with 78% and 77% of patients respectively having taken these drugs at some time. Next came Flagyl with 32%, Mesalazine (Mesasal) 29%, Azathioprine (Imuran) 27%, and Olsalazine (Dipentum) 25%. UC patients were more dissatisfied with drugs. CD & IC patients had more undesirable side effects. 45% said drugs controlled disease, 27% said they controlled disease but caused undesirable side effects, 28% said drugs did not provide adequate control.

SURGERY

CD accounts for 66% of survey base but 92% of operations recorded. The most operations per patient = 26. 52% of CD patients had had an operation, but only 16% of UC patients.

OTHER TREATMENTS

46% had tried a special diet. 41% had attended various alternative medicine practitioners. 32% had had surgery and 7% total parenteral nutrition.

STOMAS

57 patients have a stoma, 53% are considered permanent of which 83% have CD.

ALTERNATIVE MEDICINE

45% of CD and IC patients had made attendances to alternative medicine practitioners whereas only 33% of UC patients had. 45% of females had sought help and 32% of males.

ENVIRONMENTAL CONSIDERATIONS

ADDRESS

74% were living in a major urban area when they first had symptoms, 20% in other urban areas and 6% in a rural area. (This reflects general population distribution in Queensland.)

EMPLOYMENT

One third were clerks or did home duties (reflecting higher % of females in survey). 20% were children or in early adulthood when symptoms first arose.

CAUSES OF RELAPSES OR EXACERBATIONS OF IBD

Total responses showed patients' beliefs as to causes to be emotion/stress (45%), dietary factors (32%), infections (10%), antibiotics (8%), other drugs (3%), other causes (2%). There was no significant difference between CD, UC and IC. 79% did not feel that they had relapses at any particular time of the year but of the 21% patients who did, the months of December and January (Australian summer) show the most instances and April (Australian autumn) the least.

FURTHER STUDIES

347 (69%) were willing to keep a regular diary of various life events and environmental factors.

OTHER DETAILS

CURRENT STATUS

51% were symptom free on maintenance drugs, 30% experiencing a flare-up and 18% drug free and symptom free.

HEARD OF IBD BEFORE

84% of patients had not heard of CD before diagnosis and 81% not heard of UC.

WHERE MOST INFORMATION ABOUT IBD HAD BEEN OBTAINED

47% had received most information from ACCAQ reflecting the fact that the survey base comprised members or people who had contacted ACCAQ. However, it does indicate that when contacted, ACCAQ were able to assist with more information than obtained elsewhere. Physicians and surgeons accounted for 37%.

IBD REGISTER

471 names are on the register, 33 of which are children.