



NACC 2007 Survey of Young People with Colitis and Crohn's Disease

Introduction

The first major survey of nearly 1,000 young people with Colitis and Crohn's Disease reveals that these life-long Inflammatory Bowel Diseases (IBD) have a dramatic impact on their lives. The National Association for Colitis and Crohn's Disease (NACC) posted questionnaires to 3,000 young NACC members aged between 16-29 years to better understand how the diseases affect their day-to-day lives and gauge their views on the need for information and support. The analysis was carried out by Oxford-based NSM Research.

974 (32%) members responded and the survey has highlighted a huge need for improved support and information for young people to help them understand and better manage their conditions.

Demographics

The male/female ratio of responses was 26% male / 73% female. The average age of the survey responders was 25 years old. and 43% were under 25 years old. 63% had Crohn's disease, 39% Ulcerative Colitis and 1% another unspecified IBD. There were responses from all over the UK, with 21% from the North, 15% from the Midlands, 4% East Anglia, 9% Greater London, 27% from the South East, 7% from the South West, 4% from Wales, 7% from Scotland and 3% from Northern Ireland.

Diagnosis

The average age of diagnosis was 20 years old. 10% of responders were diagnosed by their GP; 7% by a paediatrician or paediatric gastroenterologist; 69% by their gastroenterologist; 15% by their surgeon and 1% by their IBD nurse. A third of the young people (36%) waited less than 3 months between seeing their GP and having their diagnosis confirmed, while 24% waited between 4-6 months, 9% between 7-9 months and 29% waited more than 10 months for a confirmed diagnosis.

Disease Profiles

Disease flare-ups were reported as occurring at least once in the previous year by 75% of the young responders. Twenty six per cent reported having had one flare; a further 26% reported 2-3 flares and 24% had suffered more than four flares in the last year. These serious levels of illness resulted in 46% of responders having to attend hospital more than four times in the previous year, with 34% of responders being admitted to hospital and 33% undergoing major surgery.

Nursing Support

Nearly half of responders (49%) were lucky enough to have access to an IBD Specialist Nurse, 28% were not as lucky and did not have a nurse, while the remaining 23% did not know whether they have a nurse or not. Only 20% of responders' hospitals offered an IBD Helpline, 27% did not have access to a Helpline and 52% of responders were not aware of one.

Of the 20% with access to a nurse Helpline, approximately 22% of responders had made good use of it calling it more than 3 times in the previous year, 10% had called their Helpline twice and 21% had needed to call it once, with a further 33% not requiring one. When asked who they contacted when a disease flare occurred, the majority (43%) call their gastroenterologist, 36% their GP and 35% their IBD Nurse.

Symptoms

Over 80% of the 974 responders reported their most serious symptoms as being urgent diarrhoea, pain and severe tiredness when the disease is active. These three symptoms were all ranked as being either a 'One' or 'Two', on a scale of One to Nine, where a 'One' indicates the most severe form of the symptom. On the same scale, fever was reported as being a problem for 36% of responders who graded it between 'One' to 'Three'.

Loss of weight, loss of appetite and anaemia were all ranked as 'Three', on the scale of 'One to Nine' for 49% of responders, with sickness, joint pain and constipation also being reported while the disease is active.

During remission, 63% of young responders stated that urgent diarrhoea was still a serious problem with pain being reported similarly by 61% and tiredness being regarded as the biggest problem for 79% of people. Fever, loss of appetite, weight loss and anaemia were all ranked as a 'Three' by a quarter of respondents.

Hospital Support Staff/Services

When asked what types of support staff are available, 49% of young responders had access to a dietitian, but less than 10% had access to either a psychologist or counselling and only 13% were offered Group Meetings for people with IBD. All these issues were regarded as needing improvement in addition to making information about the illness more available, increased accessibility to the IBD nurse or gastroenterologist, increased numbers of IBD nurses and better communications overall.

Impact on School, Work and Relationships

Not surprisingly the survey underlines the profound effects that Colitis and Crohn's Disease can have on the education, careers, social lives and relationships of young people. From the nearly 1,000 respondents, 15% reported that they are at college, university or in higher education, 61% are employed full-time and 13% are employed in part-time jobs. Only 2% are unemployed or looking for work, but a significant cause for concern is that 9% are unable to work due to their illness.

When asked about communications with teachers, employers, work colleagues and friends, only 25% of young people had talked to their teachers about their illness, but it would seem that as they get older and possibly more confident, 67% had discussed their condition with their employer and work colleagues.

Previous studies have shown that young people can find it difficult to discuss their illness especially in the early days with friends, but in this survey it was reassuring to find that the majority or 91% had discussed their Colitis or Crohn's Disease with friends.

When asked what help their school, college, university or employer had given them, 23% of young people reported a sad lack of support, with only 1% stating that they were given extra help and only 2% stating that they were treated with leniency when absent. However, on the plus side, 18% said that they had been treated with understanding and sympathy, 16% were given time off for doctors/hospital appointments and 10% were given time off to recover when ill.

Taken overall it would appear from these mixed findings that there is still a vast room for improvement in terms of the general public's support and understanding of Colitis and Crohn's Disease, especially among young sufferers.

Social Impact of Colitis and Crohn's Disease

When assessing their overall ability to attend school, work and relate to their friends and family more than 20% stated that their disease impacted negatively on their education; 35% reported that it seriously affected their career; 51% their social life and 17% of responders felt that it seriously affected their ability to find a partner.

Feelings of Isolation

A less obvious consequence of Colitis and Crohn's Disease is the isolation brought about by needing to be near a toilet combined with the symptoms of pain and tiredness. Forty three per cent of young people reported feeling seriously isolated at the time of their diagnosis and 20% said they are still affected by isolation today.

When asked for general comments about their illness and the way it had impacted upon their lives, 246 young NACC members stated that their disease made socializing almost impossible and another 235 members stated that it seriously affected their work, in that they could not work or that the disease made it difficult for them to get a job. Tiredness and lack of energy was cited by 209 members as their major issue and this was followed by 183 members stating that 'always needing to know the proximity of a toilet' most affected their lives. Needing to be careful about what they eat was a serious issue for 165 respondents and 118 stated that their education had been badly affected with some responders having been forced to leave their school or university because of their illness.

For 91 NACC members, pain and cramping were their most serious problem and for another 91 difficulty in having or sustaining a relationship was their most serious issue as a result of their Colitis or Crohn's Disease.

Sources of Information

When asked where survey responders had found their most helpful information, the majority cited a NACC information source such as the Newsletter, Information Booklets, Can't Wait Card, Website, Meetings, the new "IBD and Me" website area and the NACC Helpline. Family and friends ranked highly for approximately one quarter and IBD nurses were important information sources for 90 members. For 54 responders, the chance to speak to other people with Colitis or Crohn's was an important information and support resource.

Overall, the 974 responders have been members of NACC for an average of 3.7 years. When asked why they had joined NACC, 490 (55%) responses cited a need for information about their disease which would enable them to improve their understanding of their diagnosis. A further 180 stated that they needed support. Forty four members were recommended to join by their consultant and 44 wanted the latest news and updates from NACC. Other motivations were a need to support NACC and raise awareness of IBD and 40 other members joined so that they could meet others with Colitis and Crohn's Disease and learn about other patients' experiences.

The Role of the Hospital

Hospitals not surprisingly play a key role in pointing newly diagnosed young people towards NACC. Nearly 500 survey respondents stated that hospital staff had informed them about NACC while the NACC posters and IBD Booklets also played important parts in helping young people find the charity. One hundred and sixty people found NACC via a search engine and once again, family, friends and the press or library helped raise awareness of NACC.

NACC Meetings for Young People

A small proportion of young responders (6%) currently attend NACC Meetings and when asked what would encourage them to attend more meetings, 248 respondents said that they needed the meetings to be closer to home and a further 77 asked for greater numbers of younger members to be there.

When the young survey responders were asked whether they would attend a social event for people of their age, a resounding 59% said 'yes' and 66% stated that they would like to attend an educational one-day meeting. Asked if they would attend a one-day meeting with a facilitator to lead discussions on the various aspects and difficulties of living with IBD, 60% said they would.

For those interested in taking part in the meetings, 92% said they would be willing to pay a small charge of £10 and 86% would be prepared to travel with the majority prepared to travel for up to 2 hours. Nearly all or 95% of the responders interested in attending meetings wanted to hear more from NACC about future events.

Report prepared for NACC by Healthcare Solutions.

Data analysis undertaken by NSM Research
