

The support needs of parents with inflammatory bowel disease and their children

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In the UK there is growing interest in the support needs of disabled parents and their children, with a number of shortcomings in service provision identified. However, little attention has been paid to the experiences of families when a parent has a chronic illness. Inflammatory bowel disease (IBD) is a chronic illness with no known cure, though effective treatments are available. The two main forms of IBD, ulcerative colitis and Crohn's disease, can cause a range of debilitating symptoms, including some which are associated with considerable social stigma. This study investigated the support needed by families in this situation. The key findings were:

- Parents' main parenting difficulties were with household chores, providing for financial needs, and social activities.
- Parents were most likely to perceive their immediate family as helpful sources of support in bringing up their children. Support from statutory services came mostly from health professionals.
- Over a third of parents had high levels of psychological distress. High levels of depression were associated with greater severity of IBD symptoms, more parenting difficulties and lower amounts of support from others in bringing up children.
- Children who had a parent with IBD were doing well in many aspects of everyday life, but experienced more emotional and behavioural difficulties than might be expected for their age range.
- Parents' main need was for support to prevent and alleviate psychological distress. Children can best be supported by interventions targeted at their parents, though information on the condition and its treatment would also be valued.

Background

Research exploring the impact of IBD on parents and their children was first carried out between 2000 and 2002. This qualitative work suggested IBD could create difficulties for parents with the condition and their children, and provided a useful insight into the support parents and children might find valuable. However, in order to assist service providers in making decisions about how best to help families, it was important to establish the prevalence of the difficulties reported, factors that influenced outcomes, and parents' and children's priorities regarding support. For these reasons, two quantitative surveys of parents with IBD and their children were carried out. The objectives were:

- ▼ To describe parents' difficulties with parenting tasks, psychological distress, and the support they received from others in relation to parenting.
- ▼ To describe children's responsibilities within the home, social activities with peers, relationships with parents, emotional and behavioural difficulties, and prosocial behaviour.
- ▼ To identify parents' and children's met and unmet support needs.
- ▼ To investigate factors associated with any psychological distress experienced by parents with IBD and any emotional and behavioural difficulties experienced by their children.

Findings

Survey of parents

One hundred and seventy-eight people took part in the survey. They were recruited from two sources: the National Association of Colitis and Crohn's Disease (NACC) and gastroenterology clinics. Most respondents (80 per cent) were female. They had between one and four children under the age of 16 living at home, with a mean age of 9 years.

Parenting difficulties

Parents varied considerably in the extent to which they experienced difficulties with parenting. When parents did have difficulties, these were most often in relation to household chores, providing for financial needs, and social activities. It was rare for parents to report having difficulty with being physically affectionate, or talking and listening to their child.

Support from others

Parents varied widely in the extent to which they reported that others had been helpful to them in bringing up their child during the past three to six months. Parents were most likely to perceive their immediate family as helpful sources of support, with the partner/spouse most frequently named as 'very' or 'extremely helpful'. In relation to statutory services, parents were most likely to consider hospital-based health professionals as helpful sources of support, followed by General Practitioners, but only a small proportion rated them as 'very' or 'extremely helpful' (18 per cent and 15 per cent). Social services received very low ratings on helpfulness, though this can partly be explained by few parents being in contact with social services.

Psychological distress

Parents' psychological distress was assessed via a measure of symptoms of anxiety and depression over the previous week. In total 37 per cent of parents reported experiencing feelings of anxiety, and 16 per cent feelings of depression, that were severe enough to suggest they might need psychological support. These rates are higher than those reported in a community sample considered to be broadly representative of the general adult UK population in terms of age, gender and occupational status, and in studies of IBD patients attending outpatient clinics.

The data were analysed to determine which factors were associated with parents' psychological distress. Parents' anxiety was not well explained by the variables available from the survey. In the analysis of parents' depression, the significant predictors of depression were *perceived severity of IBD symptoms*, *parenting difficulty*, and the *interaction between support from others and parenting difficulty*. Increases in perceived severity of IBD symptoms and in parenting difficulty were associated with increases in depression. In relation to the interaction, when parenting difficulty was low, family support made very little difference to parental depression. However, when parenting difficulty was high, support from others in bringing up their child/ren greatly reduced parental depression.

Parents' unmet support needs

The survey revealed a number of areas of *unmet* needs (i.e. 'Need this and *not* getting it'). Box 1 lists unmet support needs reported by more than 50 per cent of respondents. These are listed in rank order, with advice on stress management the most commonly reported unmet support need.

Survey of children

Seventy-four children, aged between 11 and 16 years (mean age 13 years), were recruited to take part in this survey via respondents to the parents' survey. Forty (54 per cent) were male and 34 (46 per cent) female.

Box 1:

Parents' unmet support needs

- Advice on stress management
- A booklet which explains IBD to children
- Access to disabled parking to enable easy access to toilets
- Advice on explaining IBD to their child

Social life

Overall children had an active social life, and were no different from a British community sample in terms of their frequency of involvement in organised social activities for young people, how much time they spent with peers, and how often they went to visit a friend in their home. However, they were significantly less likely to have friends to visit them at home than the general population.

Responsibilities within the home

Most children spent less than three hours a week doing chores and felt that they did about the same amount to help around the home as their peers. When asked about the type of tasks they were involved with, everyday household tasks were reported most frequently. Only a few described responsibilities directly related to the parent's condition. It was also rare for young people to report disruptions to school attendance because of the parent's illness.

Relationships with parents

Most young people had a good relationship with their parents, with quarrelling infrequent and talking about things that matter frequent.

Emotional and behavioural difficulties

Despite these positive findings, a substantial proportion of young people (18 per cent) reported emotional and behavioural difficulties severe enough for them to be considered at risk of clinically significant difficulties that warrant intervention. In addition, when parents were asked about their children aged between four and 16 years, they reported that 31 per cent of this age group were experiencing such difficulties. These rates are significantly higher than reported in a recent British community sample.

The data were analysed to determine which factors were associated with self-reported and parent-reported emotional and behavioural difficulties. These analyses were based on small samples of children and are therefore exploratory.

Analysis of self-reported emotional and behavioural difficulties showed that the significant predictors were the *frequency of talking to their father*, and the *frequency of arguing with their mother*. As the frequency with which young people talked to their father about things that matter increased, self-reported difficulties scores were reduced. As the frequency with which a young person argued with their mother increased, self-reported difficulties scores increased. Since most of the parents with IBD were mothers, this suggests frequency of arguing with the ill parent and talking with the well parent were associated with children's difficulties.

In the analysis of children's emotional and behavioural difficulties as reported by parents the significant predictors were *the child's age*, *parenting difficulty*, and *whether the child has an illness, health problem or disability*. Increases in child age were associated with a reduction in difficulties. Both the child having an illness, health problem or disability, and increases in parenting difficulty, were associated with an increase in these parent-reported difficulties.

Prosocial behaviour

Prosocial behaviour was assessed via a measure which asked about the extent to which a child is considerate of other people's feelings, shares and is kind to other children, is helpful if someone is hurt, upset or feeling ill, and volunteers to help other people. Based on parent-reported data, girls displayed more prosocial behaviour than boys. Comparison of the survey scores with those obtained in a British community sample suggested they were not substantially different.

Children's unmet support needs

Compared to their parents, young people reported few support needs. Just over a third had an unmet need for information and advice about their parent's health. Less than twenty per cent said they had an unmet need for someone to talk to, to meet other young people whose parent was unwell, and for help around the home.

Recommendations

Support for parents

Parents' main need is for support in dealing with psychological distress. Practitioners can prevent psychological distress arising by:

- ▶ Interventions aimed at improving the parent's health.
- ▶ Encouraging parents to seek out help with parenting tasks from informal sources (spouses/partners, family, friends).
- ▶ Assisting parents in accessing help from social services and local education authorities when informal support with parenting is unavailable.

In situations where parents are already distressed, they may benefit from psychological support. The research suggests they are likely to be receptive to advice on stress management and counselling.

In addition to support with psychological stress and distress, parents should be offered help in explaining their condition to children and in accessing disabled parking.

Support for children

Service providers can help children by:

- ▶ Supporting parents in the ways listed above, since this may reduce the likelihood of children developing emotional and behavioural difficulties.
- ▶ Providing children with information about IBD and the parent's condition.

Methods

Two cross-sectional postal surveys were carried out between June 2002 and March 2003: one of parents with IBD, and the other of their children. Both surveys included a number of standardised scales, as well as checklists and questions designed for this research. There were two parts to the data analysis. First, a description of parents' and young people's experiences and support needs. Second, regression analysis was used to determine which factors were associated with parents' psychological distress, and children's emotional and behavioural difficulties. Variables were entered into the regression equation hierarchically, with health and other parent and child variables entered after controlling for socio-demographic variables.

The survey of parents involved 178 people. One hundred and twenty-five were recruited through NACC via an advertisement placed in a newsletter. Ninety-seven per cent of those who responded to the advertisement, and were eligible for the survey, returned a questionnaire. A further 53 parents were drawn from four gastroenterology clinics in England. They were recruited via an information leaflet and screening questionnaire sent to all patients aged between 18 and 65 years, who had a diagnosis of IBD. Eighty-four per cent of those who returned a screening questionnaire, and were identified as eligible for the survey, took part in the survey. Survey respondents ranged between 23 and 65 years (mean age 38 years). They had experienced symptoms of IBD for between one and 35 years (median 10 years). On a standardised measure of perceived IBD-related health status, scores were similar to those reported in other samples of people with active IBD. The majority of parents (88 per cent) were living with a partner. Respondents were drawn largely from households classified as representing managerial and professional occupations (57 per cent), though all other socio-economic classifications were represented.

The survey of children involved 74 young people, drawn from 59 families, recruited via participants in the parents' survey. This represents a response rate of 72 per cent. Parents of 50 young people were recruited through NACC, and the remainder through gastroenterology clinics. Most respondents had two parents living at home (92 per cent). It was usually the young person's mother, rather than father, who had IBD. The socio-demographic profile of their families was similar to that reported in the parents' survey. However, their parents had experienced symptoms of IBD for longer than in the larger sample and undergone more medical interventions.

Preliminary analysis of data from both surveys revealed few differences between respondents recruited through NACC and those recruited through gastroenterology clinics, so the samples were combined.

NACC (www.nacc.org.uk) provides information and support for people with ulcerative colitis or Crohn's disease. There is a national support line, NACC-in-Contact, on 0845 130 3344

Further information

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Related *Research Works* include Mukherjee, S. and Sloper, P. 'Impact of Inflammatory Bowel Disease on parents and their children', March 2001.

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