

# Impact of inflammatory bowel disease on parents and their children

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RESEARCH FINDINGS FROM THE  
SOCIAL POLICY RESEARCH UNIT

SPRU

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Inflammatory bowel disease (IBD) is a chronic illness which has two main forms, Crohn's disease and ulcerative colitis. The condition can have wide ranging effects on everyday life, and is likely to pose problems for parents bringing up children. However, it is striking that there has been no previous research on the experiences of parents who have IBD nor on the effects on their children. This study, funded by a NACC Social and Psychological Research Award, set out to investigate these topics in interviews and focus groups with parents who have IBD. The key findings were:

- When parents were experiencing symptoms of diarrhoea or incontinence, caring for young children was difficult, social activities and holidays were restricted, and taking children to and from school or attending school events was problematic.
- Pain and tiredness made parents more likely to be irritable with their children and to lack the energy needed to look after younger children.
- Having to spend time in hospital caused problems for parents of young children.
- Parents noticed both positive and negative effects on their children. On the one hand children seemed to be more caring and understanding of illness. On the other, they were anxious when the parent was ill or in hospital, and reacted with frustration or anger to restrictions imposed on their own activities by the parent's illness.
- When they were unwell, most parents turned to family and friends for support, but they received very little support from health and social services. They wanted these services to provide more practical support, such as a crisis support service; more information about the effects of IBD on family life; more opportunities for children and partners to meet others in their situation; and to take family circumstances into account, especially when arranging treatment.

## Background

Inflammatory bowel disease is a chronic, relapsing condition. Symptoms include diarrhoea, pain, fatigue, weight loss and fever. A recent survey of 2,400 people with IBD found that nearly half were worried about the effects of their condition on family members other than their partner. These worries included concerns about the effects of the condition on their ability to care for their children. However, there has been no previous research investigating the experiences of parents who have IBD, or the effects of their condition on their children. Previous research on the effects of other parental illnesses on children, whilst sparse, suggests that such children are at slightly increased risk of problems such as anxiety and depression.

Information on the experiences of parents with IBD and their children is needed to better equip professionals in health and social care to offer appropriate advice and support to parents. This study aimed to investigate:

- ▼ how IBD affects people in their parenting role
- ▼ effects parents have noticed in their children
- ▼ ways used to deal with difficulties
- ▼ support needed by parents with IBD.

## Findings

### The effects of IBD on parents

The symptoms of IBD had wide ranging effects on family life and caring for children, particularly during flare-ups of the condition (see Figure 1).

Incontinence and diarrhoea restricted the family's social activities, making it difficult for

**Figure 1**  
**Effects of IBD on parenting**

#### Difficulties

- Difficulties in caring for young children
- Restrictions on social life and holidays
- Problems taking children to and from school and attending school events
- Reluctance to visit homes of children's friends
- Irritability and reduced tolerance with children
- Hospitalisation and separation from children

#### Positive effects

- Closer relationship with children

the parent to leave the house when experiencing severe flare-ups of the condition. These symptoms created different problems for parents with children in different age ranges. Mothers described the struggle involved in caring for babies and pre-school children whilst suffering from incontinence or diarrhoea. They spoke of having to feed babies whilst sitting on the toilet and being unable to leave the bathroom to attend to children who were crying. Going shopping was difficult and a number reported having to leave their children, sometimes with strangers, in order to get to a toilet urgently.

When children reached primary school age, a major problem was getting children to and from school and attending school events. Some parents were reluctant to go to other people's houses with their child, because of embarrassment about their condition. Consequently their children, could only socialise with other children in their own home.

In the secondary school years, children were more independent, but parents still faced difficulties

in attending school events. Some found that incontinence became less problematic as their children could understand their need to be near a toilet, but others found that they were more embarrassed by their condition as their children got older.

Pain and tiredness limited the family's social life and the parent's ability to spend time with young children. The care of pre-school children could be particularly difficult, with parents lacking the energy to look after, play with and deal with the behaviour of their children. Some reported that this affected their ability to show affection with their children. Their tolerance was reduced, making them irritable and short tempered.

Treatment of IBD can require regular hospital visits and periods in hospital. Parents were concerned about children seeing them unwell or attached to machinery and tubes when in hospital, and some limited their children's visits. Returning home after hospitalisation was also problematic, since it was difficult to care for children when not fully recovered.

These difficulties caused worry, fear and guilt for parents. They spoke about fear of having an accident whilst out with their child, of being scared to go out for fear of losing their dignity, and of being exhausted by social events or holidays because of the time spent worrying. They also worried about whether the condition was hereditary. The restrictions the condition placed on family life led to feelings of guilt and a number of mothers spoke of periods of depression.

Despite these negative effects of IBD on parenting, parents also noted some positive effects. The main one was developing a closer relationship with their children as a result of their condition. As one mother explained

*'if you can talk about bowels, you can talk about anything.'*

### The effects of parental IBD on children

Most parents reported a mixture of positive and negative effects on their children; a few had not seen any effects. Children in the same family varied in their reactions. Parents thought that the effects on children were probably greater when it was the mother rather than the father who had IBD, as when fathers are ill there is usually still a mother around to care for the children.

Showing more care and consideration, both towards the ill parent and to people more generally, was most frequently mentioned as a positive effect on children, along with being more independent, and developing closer relationships within the families.

The most common negative effect was restriction on children's social activities. Others were children not having a parent with sufficient energy to play with them and missing out on parents attending special events. The negative reaction parents noticed most often in their children was anxiety or worry about the parent being ill or going to hospital. A number of parents said their children reacted with anger or frustration to the restrictions imposed by the illness and others felt that their children were embarrassed by their condition.

**Figure 2**  
Effects of parental IBD on children

#### Positive effects

- Being more caring
- More independent

#### Negative effects

- Restrictions on some activities
- Anxiety and worry
- Frustration and anger
- Embarrassment

### Dealing with difficulties

Parents used a variety of strategies to deal with the effects of IBD on themselves and their children. The most common strategy was turning to others for support, including practical help in caring for children and emotional support for both parent and child. The most important sources of this support were partners and members of the extended family. Only a small number of people turned to friends and neighbours for help. Some said they did not want to tell people outside the family about their condition or did not want to impose on others. Single parents and those who had no family members living nearby had particular difficulties in getting support.

A few people had been able to meet other parents with IBD and they had found this useful. Where parents had been able to explain their difficulties to staff at their children's schools, they had found them extremely helpful in matters such as understanding that the children may be late some days and ensuring that the parent had easy access to toilets at the school.

Other coping strategies included making every effort to control symptoms by taking medication at the first sign of a flare-up and keeping fit. The parents who had an ileostomy spoke of the benefits in terms of regaining freedom and control over their everyday life. Some parents had decided to have just one child or had left a substantial gap between children so that they did not have to care for more than one child under school age.

Parents tried to think positively about their situation, and used jokes about the condition to diffuse tension in the family:

*'Any kind of problems with bowels and gas and being in a car, an enclosed space with kids, I mean we just laugh, you know, we just fall about laughing.'*

Many people tried to avoid situations which may be embarrassing, such as shopping trips and school events, but as noted earlier, this meant increased restrictions for their children.

Parents varied in the extent to which they talked to their children about the condition. Some restricted the information they gave to children as they did not want to worry them; others were very open about their condition. Those who had given children information reported that it had been helpful.

### Support needed

**Figure 3**  
Support wanted by parents

- Practical assistance
- Information for parents and children
- Awareness raising about the condition
- Support in coping with the condition

Practical support encompassed a crisis support service to help when parents were ill; services to enable them to receive home treatment rather than going into hospital when having bowel rest and tube feeding; and recognition of their needs by social and housing services – for instance, enabling easier access to disabled parking and provision of more than one toilet in their homes.

Parents wanted more information on the effects of IBD on pregnancy and family life, ileostomies, and what to expect after surgery. They also wanted a book written for children which explained IBD.

Awareness raising about IBD was felt to be important for three groups: generic health staff such as GPs, nurses and health visitors; retail companies who could ensure a more positive response when parents

asked for access to toilets in shops; and teachers and pupils in schools.

Support in coping with the condition was important for parents and their partners. They felt that generic health staff should be more understanding, and that health services for IBD should take more account of their family situation when arranging treatment. In addition, they thought it would be helpful to have opportunities for themselves, their partners and their children to meet other families in which a parent has IBD.

## Implications

It was striking that although parents were facing wide ranging effects on family life, few had received support from health or social services in dealing with this. The needs of this group of parents are somewhat hidden: health services focus on treatment of the condition; services, such as social services, who are usually involved in supporting parents are unlikely to recognise the needs of people with IBD; and parents are reluctant to discuss their difficulties, as the symptoms of the condition carry a strong social stigma.

A recent Social Services Inspectorate report, *A Jigsaw of Services* (2000), recognises that provision of support to families where a parent has a chronic illness or disability is hindered because the needs of the families fall between adult and child services. Greater coordination between these departments within social services is needed. However, even where appropriate services are available, parents with IBD may have difficulty accessing them as the condition is fluctuating and they are not generally recognised as disabled.

Health services need to take a more holistic approach to IBD and, where necessary, liaise with other services in the community, including social services, to ensure that parents and their children obtain appropriate support. The promotion of a primary care led NHS and moves to roll out services from acute hospital settings to the community provide a number of opportunities for this group. Parents themselves wanted to avoid hospital admission as much as possible and some treatments, such as tube feeding, are already provided in the community for other groups. However, if the needs of parents with IBD are to be met, awareness raising about the condition is needed both

within health services, where generic staff may have little understanding of the needs of people with IBD, and in the wider community, including social services departments, local education authorities and housing departments.

## Methods

The project was funded by the National Association for Colitis and Crohn's Disease, and carried out over six months, commencing April 2000.

Parents were recruited from two hospitals in the North of England. Twenty four parents, five fathers and 19 mothers, took part. Fifteen parents had Crohn's disease, eight had ulcerative colitis and one had proctitis. Fourteen parents had undergone surgery because of their IBD and seven had an ileostomy. Parents' ages ranged from 26 to 54 years, and the time they had been experiencing symptoms of IBD varied between two and 36 years. They had between one and four children each, varying in age from one to 22 years. There were a total of 47 children in the families involved in the study. Most parents were living with a partner, three were single parents.

Thirteen parents attended one of four focus group meetings. Eleven parents, who were unable to attend focus groups, were interviewed individually.

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### Further information

Copies of the full report *Understanding the impact of inflammatory bowel disease on parents and their children* by Suzanne Mukherjee and Patricia Sloper are available from SPRU's Publications Office, price £5.00.

Contact Ruth Dowling  
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