
**UNDERSTANDING THE IMPACT OF
INFLAMMATORY BOWEL DISEASE
ON PARENTS AND THEIR
CHILDREN**

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*Suzanne Mukherjee
and
Patricia Sloper*

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UNDERSTANDING THE IMPACT OF INFLAMMATORY BOWEL DISEASE ON PARENTS AND THEIR CHILDREN

REPORT TO NACC MEMBERS

A recent survey of NACC members found that nearly half were worried about the effects of their condition on members of their family, other than their partners, including worries about their inability to care for their family and difficulties in coping with children. However, it is striking that there has been no research on this topic, neither on the experiences of parents who have IBD nor on the effects on their children.

Aims of the research

This was a small study to find out about the experiences of parents who have IBD and their views, both positive and negative, on:

- ▶ How IBD affects them as a parent.
- ▶ Effects they have noticed in their children.
- ▶ Ways they use to deal with difficulties they encounter as a parent.
- ▶ Support they would like from services.

About the study

Nineteen mothers and five fathers took part in the study, by attending focus group discussions or taking part in individual interviews. Between them they had 47 children, ranging in age from one to 22 years. Parents reported on their experiences over the lifetime of their children.

Main findings

- The main positive effect reported for parents was developing a closer relationship with their children by being more open with them, because of the need to explain their condition.
- When parents were experiencing symptoms of incontinence or diarrhoea, caring for very young children was difficult, social activities and holidays were restricted, 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, play with and deal with the behaviour of younger children.

- Parents who had spent time in hospital had sometimes found it difficult to arrange for care of young children.
- Positive effects noticed in children were that they seemed to be more caring and understanding of illness. The main negative effects were children's anxiety when the parent was ill or in hospital, and children reacting with frustration or anger to restrictions on their social activities.
- Parents used a number of strategies to help them deal with the impact of IBD. The support provided by family and friends was very important; trying to control symptoms and thinking positively were also mentioned. Those who had an ileostomy found that this had helped them to regain control over their everyday life. Explaining the condition to children at a level they could understand was also felt to be helpful.
- Parents wanted services to provide more practical assistance, such as a crisis support service; more support during pregnancy and after the birth of a child; more information for themselves, and information tailored for children, about the effects of IBD on family life; to take a broader view of the whole family, especially when arranging treatment; and to provide opportunities for children and partners to meet others in their situation.
- Parents suggested that NACC local groups could provide more opportunities for families to meet and get to know each other in social activities.

CHAPTER ONE: LITERATURE REVIEW

1.1 INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic illness for which there is no known cure (Thompson, 1993). There are two main forms of IBD: ulcerative colitis (UC) and Crohn's disease (CD). Prevalence and incidence rates vary globally, with the highest rates in northern countries (United Kingdom, Norway, Sweden and the United States). Here the rates vary between 150-200 per 100,000. Data available on CD reveal a general global rise in incidence rates between 1960-1987, which is interpreted as a true increase in incidence (Andres and Friedman, 1999). In the UK, monitoring of CD in the 0-19 year old age group has revealed a 50 per cent increase in incidence between 1981 and 1992 (Armitage *et al.*, 1999). It is argued that data from this study reflect a true increase in incidence, and cannot be attributed to earlier diagnosis, because they are based on the date of symptom onset rather than date of diagnosis. The data available on UC has been less consistent, and this is thought to reflect differences in awareness and detection of UC, and the availability of medical care (Andres and Friedman, 1999).

In 1995, a survey of a random sample of 2400 members of the National Association for Colitis and Crohn's Diseases (NACC) in the UK asked respondents what aspect of their condition caused them greatest worry or concern (Walters, 2000). Numerous themes emerged. However, it was notable that 42 per cent of those who responded were worried about the effects of the condition on members of their family, other than their partners. A number of respondents specifically mentioned worries about their inability to care for their family, and difficulty coping with children. These findings are in keeping with a recent review of the literature on IBD patients' experiences which notes that feeling a burden to others is a recurrent theme, and that the condition has been shown to cause family conflict and distress (Casati *et al.*, 2000).

The concern raised by people with IBD about the impact of their condition on family members is not unexpected. It has emerged as a significant issue for mothers who have a range of chronic conditions, in a number of qualitative research studies (Altschuler and Dale, 1999; Thorne, 1990; Allaire, 1988). However, overall very little research attention has been given to the impact of parental chronic illness on family members. This is surprising given that it is widely assumed that parental illness is likely to be detrimental to the child (Kahle and Jones, 1999). Furthermore, clinicians based in the UK report that little attention is paid in clinical practice to supporting parents who are chronically ill (Altschuler and Dale, 1999). They acknowledge that time constraints and limited understanding of the issues for chronically ill

parents may account for this lack of attention. However, Altschuler and Dale also suggest that this silence reflects both professionals' fear and anxiety about addressing issues related to parenting in case this distresses the parent, and feeling unequipped to provide families with help. They warn that such lack of attention is of concern because it '*can leave parents unsupported in dealing with the effect of their illness on their children, adding to the emotional stress of being ill*' (p 24).

It is striking that no research in this field, either on the experience of parents themselves or their children, has been carried out in relation to IBD. Therefore, in this review we will draw on research carried out with other conditions to gain an insight into the impact IBD *might* have on parents and their children. More specifically, this review aims to answer:

- What are the experiences of parents who have a chronic illness?
- What impact does parental chronic illness have on children?
- What conclusions can we draw about the possible impact of IBD on parents and their children?

1.1.1 The organisation and scope of the review

This review will be in four main sections. First, we provide an *overview of IBD* and the implications for parents. Secondly, we describe the *theoretical frameworks* that guide our understanding of the impact that IBD may have on parents and their children. Thirdly, we review *literature on the experience of parents who have a chronic illness*. Fourthly, we examine *evidence on the impact of parental chronic illness on children's adjustment*. Finally, we draw the chapter to a close by reflecting on the implications of the research evidence for parents with IBD and their children.

In writing this literature review we have decided to limit it to research published from 1980 onwards. There are two main reasons for this decision. First, treatment and support for patients with chronic illness, including IBD, has progressed a great deal over recent years. Secondly, family circumstances, including the extent to which people live near to other family members, expectations regarding the involvement of fathers in parenting, and the number of people living in single parent households, have altered. Such changes in the everyday lives of people with a chronic illness mean that it would be inappropriate to draw conclusions about the impact of IBD on parents and their children from early research.

1.2 UNDERSTANDING IBD

In this section we focus on understanding IBD and what the condition means in terms of everyday life for patients. We begin by describing IBD, including the symptoms, treatment,

and etiology, before going on to examine the role of stress in disease activity. This is followed by an overview of research on the impact IBD has on patients' everyday life and the factors which influence quality of life. We end by reflecting on the implications for parents.

1.2.1 Symptoms, treatments and etiology

The issue of parenting is likely to be relevant to a considerable proportion of people with IBD, since onset of the condition occurs most commonly between the ages of 15 to 40 years (Andres and Friedman, 1999; Worley, 1995), when many people will either be parents or considering parenthood. The two forms of IBD, UC and CD, cause some similar problems for the patient. Symptoms include diarrhoea, with blood and mucus, abdominal pain, weight loss, fever and sometimes vomiting. Fatigue is often prominent and perceived as disabling. Complications include anaemia, malnutrition, growth retardation in children, intestinal obstructions, abscess formation, and fistulas. There are also a number of associated diseases which affect other organs and which may be of as much significance to the patient than the IBD itself. Some, such as colitic arthritis, run in parallel with the IBD (Thompson, 1993). The clinical course of IBD is variable, with individuals experiencing periods of remission and recurrent attacks over long periods. These attacks may require frequent hospital visits and spells as an in-patient.

Treatment for both UC and CD includes drug therapy, to reduce symptoms, inflammation and suppress the immune response; nutrition, including an individualised diet and in some instances enteral feeding and parenteral nutrition; and surgery. For patients with UC surgery is curative, but may mean the patient having an ileostomy. Surgery may also be effective in patients with CD. This largely alleviates symptoms for a period of time, but the condition is likely to recur in other sections of the digestive tract (Worley, 1995; Thompson, 1993). In the long term, patients are at slightly higher risk of colon cancer and therefore surveillance through colonoscopy is recommended in some patients after the first 10 years of the disease (Thompson, 1993). Particularly in patients with CD, specific dietary treatment is often employed, for example in some patients liquid sip feeds may be used for periods of several weeks to the complete exclusion of other foods.

Although the etiology of IBD is still unknown, it is thought to result from an abnormal immune response to an environmental trigger in people who are genetically susceptible to the condition (Worley, 1995). The presence of a family member with IBD is reported to be the strongest single risk factor of developing the condition (Andres and Friedman, 1999).

1.2.2 The role of stress in disease activity

The role of stress in IBD has been debated for many years and remains controversial. One of

the main reasons for the interest in stress is that there appears to be no biological explanation as to why some patients with IBD experience relentless relapses, while others have long periods of remission (Duffy *et al.*, 1991). Furthermore, both clinicians and patients are reported to believe there is an association between stress and disease activity (Maunder and Esplen, 1999; Drossman, 1999).

A summary of studies which have examined the relationship between IBD and stress is given in Table 1. However, care is needed in interpreting the findings from these studies. First, research in this field has been criticised for lack of blind assessment, reliance on retrospective designs, and lack of comparison groups (Levestein *et al.*, 1994; North *et al.*, 1990). Secondly, researchers have employed a range of measures to assess stress and disease activity, sometimes tapping very different variables. For example, in relation to stress some researchers have assessed stressful life events, whereas others have investigated patients' daily hassles. Disease activity has been assessed using both scales which measure patients' self reporting of symptoms and results from endoscopic examinations. The use of endoscopic examination has come about because of concern that symptom reporting is open to recall error, with biological tests perceived as a more objective measure of disease activity. However, recently it has been proposed that symptom exacerbation in the absence of acute inflammation is an indication that stress causes functional bowel symptoms in IBD patients, similar to those experienced by patients with Irritable Bowel Syndrome (Maunder and Esplen, 1999).

At present, it remains unclear from the psychological literature whether there is an association between stress and disease activity. Studies which employ a prospective design provide little evidence to support a link. However, it is important to acknowledge that in these studies stress has usually been assessed via measures of stressful life events. These are events hypothesised to be stressful, but not necessarily appraised as stressful by the individual who experiences them. As outlined in the next section of this review (2.3.1), theories of stress and coping suggest that nothing can be assessed as stressful unless it has been appraised as such by the individual (Lazarus, 1999). It is also notable that the two studies which assessed perceived stress (Moser *et al.*, 1995; Levenstein *et al.*, 1994) did find an association between stress and disease activity. Furthermore, while von Weitersham *et al.*, (1992) found no association between disease activity and life events, patients with IBD did report elevated feelings of being under pressure relative to the control group. Such findings suggest that further investigations using measures of stress which focus on patients' own appraisal of their experiences would increase our understanding of the relationship between stress and disease activity. It is worth noting that evidence supporting a link is beginning to emerge from research with animals. For example, a recent study of mice found that short term moderate stress enhanced the response of the colon to chemically induce inflammation (Mayers 2000, Qui *et al.*, 1999).

Table 1: Studies on the association between stress and disease activity

Author	Year	Design	Sample	Measures	Association found?
Helzer <i>et al.</i>	1982	Retrospective	UC (n=50) Chronic medical illness control group (n=50)	Paykel Life Events Scale Modified version of Crohn's Index Protoscopy examination	<i>No</i>
Riley	1990	Prospective data collection every 12 weeks over 48 weeks	UC (n=92)	Paykel Life Events Scale Daily symptom diary Relapse confirmed by sigmoidoscopy	<i>No</i>
Duffy <i>et al.</i>	1991	Prospective, monthly assessments for a 6 month period	IBD (n=124)	Schedule of Recent Experience of Stress Crohn's Disease Activity Index	<i>Yes</i> , but once health related life event stressors were accounted for, others stressors had negligible impact on health outcome
North <i>et al.</i>	1991	Prospective, monthly assessments for a 2 year period and semi-annual clinic visits	CD (n=24) UC (n= 8)	Paykel Life Events Scale Social Readjustment Rating Scale (a life event scale) Gastrointestinal Symptoms Scale Protoscopic examination	<i>No</i>
Garret <i>et al.</i>	1991	Prospective, daily diary for 28 days	CD (n=10)	Daily Stress Inventory Life Experiences Survey Diary of Crohn's Disease Symptoms	<i>Yes</i> , but only for 3 participants
Von Weitersham	1992	Prospective, 3 monthly for 1	CD (n=57) UC (n=51)	Social Readjustment Scale Questionnaire to assess feeling and Scale	<i>No</i> association between disease activity and life

	year		Healthy control (60)	measuring events considered to precipitate relapse Crohn's Disease Activity Scale	events, <i>but</i> patients did have elevated feelings of being under pressure
Levenstein, <i>et al.</i>	1994	Cross-sectional, double blind	UC: asymptomatic (n=46) symptomatic (n=32)	Paykel Life Events Scale Perceived Stress Questionnaire Protoscopy examination to assess rectal mucosa	Yes , symptomatic patients were more likely to recall major life events in past 6 months and asymptomatic patients with mucosal abnormalities had higher levels of perceived stress
Moser, <i>et al.</i>	1995	Retrospective	CD (n=82) healthy control (n=107)	Perceived Stress Questionnaire Chronic Disease Activity Inventory	Yes , but only for the subjective parts of the CDAI
Gerson	1998	Retrospective	N= 17 UC (n= 10) CD (n= 7)	Family Inventory of Life Events and Disease Schedule of Recent Experience Inflammatory Bowel Disease Severity Index	No association between disease activity and patient's experience of stressful life events, but an <i>inverse</i> relationship with stressful events within the family

1.2.3 The impact of IBD on everyday life

The impact IBD has on everyday life has been investigated extensively using various health related quality of life measures (HRQoL). Such measures assess health status from the patient's perspective, encompassing the physical, social, emotional attitudes and behaviours of an individual (Borkganaonkar and Irvine, 2000). Overall patients' quality of life has been found to be moderately impaired (Andres and Friedman, 1999). When patients' self reported HRQoL scores have been compared with those completed by family members and physicians, other people have been found to underestimate the difficulties experienced by the patient (Guyatt *et al.*, 1989).

When patients with CD and UC are compared, those with CD generally report more difficulties with everyday life. Patients with CD score lower on HRQoL measures (Borkganaonkar and Irvine, 2000; Andres and Friedman, 1999). Whereas a meta analysis of 138 studies involving patients with UC found no association between the condition and psychiatric diagnosis (North *et al.*, 1990), there is some evidence that psychosocial difficulties, such as depression and anxiety, are more prevalent in patients with CD (Andres and Friedman, 1999; Thompson *et al.*, 1993; Schwarz and Blanchard, 1990). The greater psychosocial disturbance of patients with CD has been attributed to more severe disease (Drossman *et al.*, 1991).

Compared with patients with some other diseases, people with IBD maintain good overall functioning and prognosis. For example, Framer and colleagues studied 164 outpatients (94 UC, 70 CD) and found that HRQoL scores were better than for patients with multiple sclerosis or rheumatoid arthritis (Framer *et al.*, 1992). Quality of life scores for patients with UC have been reported as similar to those who have moderate obesity or myocardial infarction, and for patients with CD scores are similar to those with symptomatic angina and hypothyroidism (Drossman *et al.*, 1991).

Studies which have used other methods of assessing the impact of IBD on everyday life also suggest patients are managing every day life relatively well. For example, when 122 randomly selected UC patients were compared with age matched healthy control groups, the two groups were similar with regard to marriage, financial status, unemployment rates, and incidence of severe family, sexual or drug problems (Hendriksen and Binder, 1980). In a smaller study involving 58 patients with CD living in the city of Cardiff, employment rates were no different from community samples (Mayberry *et al.*, 1992). However, general measures of unemployment rates may hide some of the difficulties experienced by patients with IBD. In the study carried out by Mayberry *et al.*, significantly more patients with CD had experienced long term unemployment than in the community sample. Furthermore, as a result of experiences in

employment, 30 per cent were actively concealing their illness from their employer. In the UK, a survey of NACC members carried out in 1995 (Walters, 2000) found that, while only 20.5 per cent had given up work due to IBD, a further 28.2 per cent had reduced their working hours and 11.5 per cent reported changing their job as a result of the illness.

Despite functioning relatively well compared to healthy control groups, a number of studies have found that patients report high levels of perceived stress and social strain. In the UK survey of NACC members, 30.3 per cent felt that their overall quality of life was affected a lot, and a further 58.2 per cent felt it had affected them to some extent (Walters, 2000). In Denmark, 106 patients with CD were interviewed about their family, social, and professional circumstances. When compared with an age and sex matched control group of healthy patients admitted to hospital for an acute illness, the results were highly similar. However, 54 per cent of the patients with CD felt exacerbations of their disease strained their social and professional life (Sorenson, *et al.*, 1987). This pattern is reflected in patients' HRQoL scores. When dimensions are examined separately it seems that it is the social and emotional aspects of IBD patients' everyday life that are affected rather than physical functioning (Andres and Friedman, 1999; Hjortswang, *et al.*, 1999). This pattern of results distinguishes IBD from other conditions. For example, patients who have had hip replacements tend to have HRQOL scores which reflect impairments primarily in physical functioning, and patients evaluated six months after cardiac arrest have been found to have impairments in all dimensions (Drossman, 1991).

In summary, while the assessment tools employed in studies suggest that IBD patients are functioning relatively well, it appears that many feel they are under considerable stress.

1.2.4 Factors which influence effects of IBD on patients' quality of life

Although physicians tend to focus on alleviating the physical symptoms of IBD, it is now widely recognised that the severity of the physical symptoms alone does not predict patients' sense of well-being (Casati *et al.*, 2000; Drossman, 1998). Instead, the psychological and social effects are said to be 'disease independent', and better predicted by factors such as cognitive functioning, knowledge, socio-economic status, education, personality, coping strategies, social support network, culture and beliefs (Borgaonkar and Irvine, 2000). To date, researchers have examined the influence that patients' worries and concerns, coping strategies and social support have on their quality of life.

Worries and concerns

In a recent survey carried out in Sweden of 211 patients with UC (Hjortswang, *et al.*, 1999), there were poor correlations between disease activity and HRQoL measures. Instead, 'feeling

fit and well' correlated highly with worries and concerns. These findings are significant in that they suggest that even a patient who is asymptomatic may still have worries and concerns that affect their perception of their own health.

A recent review of the limited literature available on patients' worries and concerns suggests that the most prevalent worry for people with IBD is lack of energy, which has consequences for the person's social, leisure and working life, as well as interpersonal relationships (Casati *et al.*, 2000). Other concerns are: the sense of lack of control; body image, which can be altered by medication and surgery; isolation and fear; feeling a burden on others; feeling dirty; lack of information from the medical community. The researchers note that lack of information may in part reflect that there is little in the way of knowledge about the etiology of IBD. However, patients also reported difficulty obtaining information about the psychological implications of their condition and having their psychosocial concerns dismissed.

In the UK, a survey of a random sample of 2400 members of NACC asked respondents what aspect of their condition caused them greatest worry or concern (Walters, 2000). The findings overlapped with the issues reported in the wider literature. The themes to emerge were worry about deterioration, unpredictability of relapse, cancer, surgery, incurability, lifelong treatment and its side effects, using strange toilets, incontinence, effects on the family, fear of dependency, difficulty planning for the future, problems keeping weight, and inability to socialise. When asked directly how much they worried about the effect their condition had on relationships with others, respondents were most concerned about the effect it had on relationships with family members, including their spouse or partner (50.2 per cent) and other family members (42.2 per cent). The author concludes that the difficulty experienced by patients with IBD, and the impact on quality of life, stems from the uncertainty associated with the condition, both in the short term (relapses, finding toilets) and in the longer term (uncertain prognosis, cancer). The former is said to impact on quality of life, while the latter causes underlying worry.

Gender differences have been found in the concerns expressed by IBD patients. Maunder and colleagues carried out a post hoc analysis of data collected from 343 patients with IBD who had taken part in three separate studies (Maunder and Esplen, 1999). The three samples included tertiary care patients and outpatients from gastroenterology clinics. Analysis of variance found that, after correcting for perceived symptom severity, women were more concerned than men about feelings about one's body, attractiveness, feeling alone, and having children. However, the researchers note that these concerns were not the most intense concerns of either gender. They suggest clinicians take care to pay attention to the concerns found to be intense for all

patients with IBD (e.g. energy level, medication, and uncertainty), while paying special attention to gender related issues in female patients, particularly as patients may be reluctant to raise such concerns themselves.

Coping strategies

Two studies into the coping strategies used by patients with IBD found that 'emotion-focussed' strategies were associated with decreased perceptions of health, well-being and functioning (Smolen and Topp, 1997, Kinash *et al.*, 1993). Emotion focussed coping refers to thoughts or actions aimed at relieving the emotional impact of stress. In the study carried out by Kinash and colleagues, problem-focussed strategies, which involve efforts to change the situation, were found to be helpful in relieving the stress of the illness. In patients who have undergone surgery, two emotion-focussed coping strategies - 'self-blame' and 'escape-avoidance' - were found to be negatively associated with HRQoL (Maunder and Esplen, 1999).

Social support

Despite the fact that one might expect support from friends and relations to play a role in ameliorating the impact of IBD on a patient's quality of life, there has been very little in the way of research on this factor. In the study of post surgical IBD patients previously described, perceived social support contributed to 12 per cent of the variance in quality of life, after controlling for physical symptoms and coping style (Maunder and Esplen, 1999). In a study of 17 patients with IBD and their families, poor family communication was found to be associated with recent severity of illness (Gerson, *et al.*, 1998). Disease severity was also found to be positively correlated with the level of agreement within the family about the cause and treatment of the condition. Unfortunately, the researchers did not examine HRQoL.

Reflections

While the evidence suggests that people with IBD function relatively well compared with those with other chronic illness, the nature of IBD does have implications for parents. Parents with IBD are likely to have less energy than parents who have no health problems. Families' social activities may be restricted through the need for the parent with IBD to be near toilet facilities. Some parents may experience periods of time away from their family due to hospital treatment. There may also be financial difficulties for some families due to the need for the parent with IBD to give up work or change jobs. Finally, parents with IBD may be under considerable stress, having a number of worries and concerns about their health, even at times when they are relatively well.

In addition, the research evidence points to the possibility that there will be considerable variation in the impact that IBD has on parents, even amongst those experiencing symptoms of a similar severity. If the pattern of results found in the HRQoL scores of patients with IBD are repeated in those who are parents, it seems likely that the experience of parenting will vary according to how much parents worry about their health, the coping strategies they employ, and the support which is available to them.

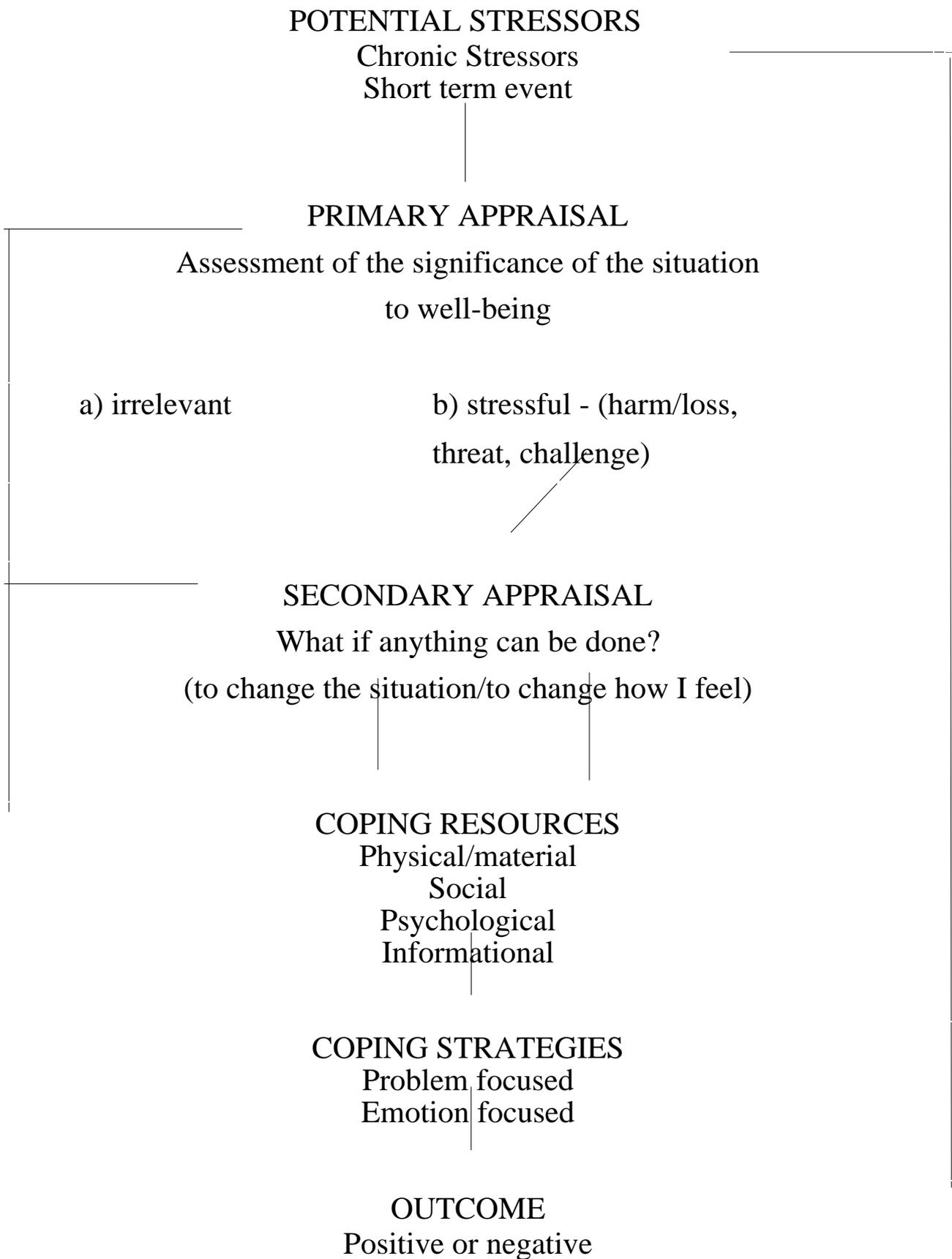
1.3 THEORETICAL PERSPECTIVES

In thinking about how parental chronic illness might affect parents and their children, and what might moderate the effect, there are a number of theoretical perspectives which give us an insight into the mechanisms which may be at work. Research on the effects of parental chronic illnesses, although fairly sparse, does indicate increased risk of problems for children, but large variability is found both within and between samples (Korneluk and Lee, 1998; Armistead *et al.*, 1995). It is clear that problems for children are not inevitable and there is a need to consider both positive and negative outcomes and to understand why outcomes vary. In order to achieve this understanding, investigation of the factors behind variation in outcome is needed, leading to identification of the particular risk or resilience factors. Such investigations can provide valuable information for services aiming to support families and reduce potential effects on children.

1.3.1 Stress and coping theory

Theories of stress and coping provide an explanation as to why individuals facing similar stressors differ greatly in the extent to which they develop stress related problems. The cognitive model developed by Lazarus and colleagues (for example, Lazarus, 1990, 1999; Lazarus and Folkman, 1984) is now considered to be one of the most comprehensive models of stress, coping and adjustment (Coyne and Smith, 1991). Figure 1 depicts this model in diagrammatic form. The model can be applied both to the parent's own reaction to the illness, and to the way the child reacts to and deals with the situation of the parent's illness and its effects on parenting and everyday life.

Figure 1: Stress and Coping Model



The central feature of this theory of stress and coping is the importance of appraisal: nothing can be labelled as stressful unless it is appraised as such by the individual. A potential stressor is initially appraised by the person as to whether or not it is 'relevant to one's values, goal commitments, beliefs about self and world, and situational intentions' (Lazarus, 1999: 75). Goal commitments are the strongest of these influences on reactions. This stage is labelled primary appraisal, and in it the person considers whether anything is at stake for them in the situation. If the answer to that question is no, the situation is irrelevant and there will be no stress. However, if the answer is yes, then we appraise whether the situation is stressful, that is whether it is harmful - damage has already occurred; threatening - there is a possibility of damage; or challenging - the situation needs to be dealt with but we feel enthusiastic or optimistic about our ability to deal with it. Threat and challenge can both occur in the same situation, but one is likely to predominate. Once a situation has been appraised as involving harm, threat or challenge, then we can decide what can be done about the situation. This is secondary appraisal, when various coping options are evaluated.

Appraisal is influenced by the characteristics and demands of the situation, but also by opportunities and resources available to the individual. Resources can be broadly categorised as: material - including income, housing, transport, belongings and other factors associated with employment status and socio-economic class; physical - including personal health, energy, strength, fitness and mobility; psychological - including values, beliefs, personality and attitudes; social - including sources of practical and emotional support, in the family and the wider community; and informational resources - information about aspects of the situation which allow us to understand events and develop plans.

These resources also influence the coping options open to us. In this model, coping refers to efforts to master, reduce or tolerate the demands of the situation. The emphasis is on what we actually think or do in attempts to manage the situation, whether or not these thoughts or actions are effective. Coping strategies include both efforts to reduce or regulate stressful emotions (emotion-focussed coping), and to alter the stressful situation (problem-focussed coping). Research on coping indicates that often both types of coping are used together (Folkman and Lazarus, 1985).

This theory of stress and coping conceives of people as active strategists in dealing with stressful situations in their lives, giving their own meaning to these situations and finding their own ways to deal with them. However, it also indicates that social, economic and cultural

factors constrain the choices individuals are able to make and influence the meaning given to events. Thus the model is transactional and the outcome of the coping process is dependent upon a multiplicity of factors. The outcome can be seen in both the short and the long term. In the short term, the person assesses the extent to which the situation has improved or been resolved, and if it is still stressful may use different coping strategies. A stressful situation which is successfully resolved can leave the person feeling stronger, and thus with strengthened coping resources for the future. However, if the situation is not resolved, the continuation of the stressful experience can affect health and well-being in the longer term.

The application of this theory to the situation of parents with a chronic illness suggests a number of ways in which the illness may or may not be stressful in relation to parenting. For instance, parents may find particular symptoms of an illness stressful because they limit their ability to care for their child. This is likely to be appraised as threatening or challenging when 'good' parenting is an important goal commitment for the parent and part of his or her value and belief system. If support from others who can substitute for the parent, possibly a partner or grandparent, is readily available and both parent and child are happy with this, the situation may be found challenging, thus prompting the parent to cope by mobilising support. However, if such support is not easily accessed, the situation is more likely to be seen as threatening, again prompting the parent to assess what can be done, but with available resources constraining the coping strategies open to the parent. If the parent can find ways of coping which resolve the situation or reduce the negative emotions produced by the appraisal of the situation, then the risk of longer term effects on health and well-being is reduced. However, if the parent's coping options are severely limited and strategies used are unsuccessful, distress is likely to be manifest, for instance in feelings of helplessness, low self esteem or depression. In contrast to this scenario, the symptoms of the illness which limit the parent's ability to care for the child may not be viewed as stressful in the first place if child care is not seen by the parent as an important and central part of their role and value system, perhaps because the child is older and needs little direct care or because that parent is not the child's main carer. In this case, no coping efforts will be needed.

1.3.2 The family systems-illness model

Like theories of stress and coping, the family systems-illness model (Rolland, 1999) suggests that illness is a potential source of stress to the whole family. This model highlights the role that the illness characteristics and the time phase of the illness play in determining whether or not the illness strains the family.

By drawing attention to the illness characteristics, Rolland provides an explanation as to why

there may be variability in the impact that different illnesses have on family members. The model proposes that the psychosocial demands an illness places on the patients and their families will vary according to the 'onset', 'course', 'outcome', 'incapacitation' and the 'level of uncertainty' about its trajectory. According to the model, IBD would be a source of strain for the family because of its episodic course, and the incapacitation and uncertainty involved.

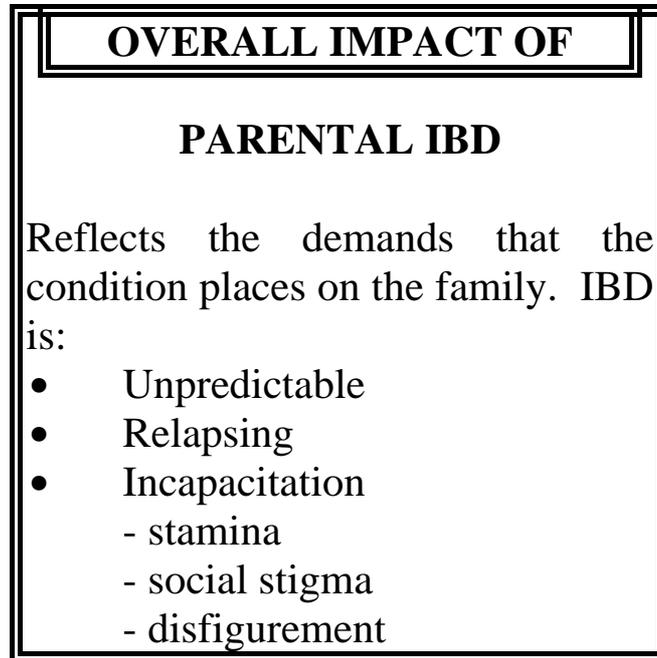
IBD follows an episodic course, in which the family moves between crisis and non-crisis situations. This transition, and the uncertainty of when a crisis will reoccur, is said to strain families. In relation to incapacitation, it is hypothesised that family stress will vary according to the extent, timing and kind of impairment (cognitive, sensation, movement, stamina, disfiguring, and those with social stigma). For patients with IBD, impairment will be in relation to stamina, and social stigma. For those who have had surgery there is also the possibility of disfigurement. In addition, patients' movements may be restricted by feeling that they need to be near to toilet facilities during flare-ups. Finally, uncertainty will clearly be an issue for patients with IBD, both in terms of day to day life and the long term prognosis. Rolland suggests that the unpredictability of an illness is the most significant source of strain for families, hindering plans for the future.

In terms of the time phase of the illness, Rolland suggests that it is important to pay attention both to the different phases of a patient's illness and to the family life cycle. Different phases (crisis, chronic, terminal) place different demands on the family. The impact these demands have on the family are said to vary according to the stage of the family life cycle, with greatest difficulty experienced when a chronic illness develops during the child rearing years, when the care-giving resources must be juggled between the children and the ill parent.

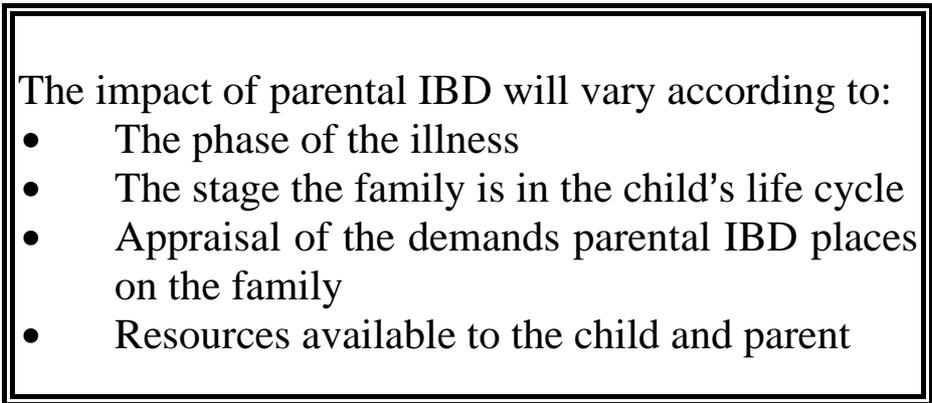
1.3.3 Reflections

Taken together, the theoretical models outlined suggest that in order to understand the impact of parental illness on parents and their children it is worth exploring both factors related to the illness itself and factors which may explain variability in the way people respond to a given illness. These factors are summarised in Figure 2. It is clear that there is some overlap between the theoretical models, with both suggesting that the impact of parental illness will vary depending on the resources available to the family. In the next part of this review we describe the research evidence on the impact of parental illness and reflect on the extent to which this supports the various theoretical models.

Figure 2: Factors hypothesized to play a role in the impact of parental IBD on children's adjustment



**VARIATION WITHIN PATIENTS ON THE
IMPACT OF PARENTAL IBD**



1.4 THE IMPACT OF PARENTAL ILLNESS: PARENTS' EXPERIENCES

Few researchers have looked specifically at the experience of being a parent with a chronic illness. In reviewing the literature we have identified three studies: two are based on research with parents with rheumatic disease and one on parents with a range of chronic conditions.

Allaire (1988) carried out a small scale study in the United States into the experiences of parents with rheumatic disease. Research into rheumatic disease may give us some insight into the experiences of patients with IBD since there are some similarities between the conditions. Rheumatic disease results in extreme tiredness, malaise and weight loss, and has an episodic course with patients experiencing periods of remission and flare-ups. Allaire's study involved a survey of 25 mothers, addressing the problems they faced and how they coped.

Mothers reported worrying about their ability to do things for and with their children, being dependent on children, and periodic absences during acute episodes. Mothers felt there were some positive outcomes for the child, including feeling that they spent more time talking to their children than other mothers; that it was beneficial for the family to have to 'slow down'; that the child's ability to cope had been strengthened through watching them face adversity; and that their children were more compassionate. The report on the study is written as guidance for nurses in contact with women with rheumatic disease, and as result the information on how mothers coped is not reported in detail. Instead, Allaire focuses on the advice offered by participants to mothers, which was as follows:

- Help from others cannot be counted on unless mothers 'trade off' favors, for example offering child sitting services in return for someone giving the children a lift to school.
- Explain when you are not well so that the child does not think they have caused the mother's stress.
- To reduce the child's worries, discuss illness and hospitalisation, using the child's questions to guide what and how much to say.

Allaire suggests that there are a number of ways that nurses can support mothers. These are:

- Exploring options for day time care of young children when the mother is in too much pain to provide care.
- Ensure that support is in place during the night for mothers with babies, either by checking that another adult is available to provide child care, or by adjusting the mother's medication so that she has some relief from symptoms.
- Coach the mother in asking for help from within and outside the family.
- Allay children's fears about developing the illness.

In the UK, le Gallez (1993) also carried out a qualitative research study with 22 patients with severe rheumatoid arthritis. In this study the interview covered a number of issues related to family life. Interviews with parents and their well partners revealed that the condition had repercussions for the whole family, but that the degree of disability did not seem to be crucial in determining how the family were coping. The author reports that many families who had a severely disabled member were 'coping' better than those with a less disabled member, though it is not clear what the author meant by 'coping'. In terms of the patient's role as parent, the author describes a change in roles and responsibilities within the family, with the well parent taking responsibility for caring for the ill parent, housekeeping and parenting responsibilities. Since the families seemed to rely on the well partner, the author recommends that nurses involved with this group of patients be alert to situations where the patient is a single parent, as in these circumstances the burden of care may fall on children.

Thorne (1990) carried out a secondary analysis of subset of data gathered for a large qualitative study of health care relationships in chronic illness. In this study mothers had a range of chronic illnesses including IBD (n=4), multiple sclerosis (n=5), rheumatoid arthritis (n=4) and scleroderma (n=3). Nine of the sample had been ill throughout the child's life, while the other seven had become ill when the child was aged 12 or older. Five mothers had raised their children as single mothers, either due to separation or being widowed. Interviews covered experiences in being ill and in receiving professional health care for a chronic illness.

The data indicated that there were four main issues for mothers. First, they were concerned about their *ability to perform instrumental mothering tasks*. For many fatigue and mobility problems made it difficult to be involved with meal preparation, housework and other mothering activities. This was a particular problem for mothers of very young children and teenagers, who were reported to demand a great deal of energy. Furthermore, mothering activities exacerbated fatigue, which in turn curtailed mothering activities. The second concern for mothers was about *not being available for their children*, due both to fatigue and the unpredictability of acute episodes. They believed that such inconsistency reflected negatively on their reliability as a mother and was also detrimental to their child. For those with a life-threatening condition, there were concerns about whether they would be around in the future to provide care. The third concern was about being overly dependent on children for emotional and instrumental support. Many were worried that their *child was becoming independent too quickly*. Finally, mothers were convinced that their illness made a difference to their *child's socialisation*. For some this was a concern since they perceived the impact as negative (strained family communication, worry about the child being too familiar with the illness). However others identified a positive effect of their illness on their child - in some instances mothers felt their child's ability for compassion was heightened.

In relation to the support received from health professionals, mothers spoke of the fragmentation of services, with professionals responsible either for chronic illness or parents and unable to accommodate the needs of both groups. For instance, health professionals supporting people with chronic illness were said to offer advice on management of the illness which did not fit the patient's parental responsibilities and were prone to trivialise the implications of motherhood. Those who had been in touch with health professionals for advice on parenting found that the implications of the chronic illness were not appreciated. For example, the illness was not considered as a source of stress for the family. The tension between the role of being a chronically ill patient and a parent was clearly a source of strain for some parents who explained that, in order to receive health care services, they had to prove that they were ill, but that this led to loss of credibility as a mother and fears about losing custody of their children.

1.4.1 Reflections

The very limited research available suggests that being a parent itself may be a source of stress for many patients with a chronic illness. Not only does parenting place physical demands on patients, but also, for many, meeting preconceived ideas about what constitutes good parenting may be an additional strain. Conversely, being ill may be seen as a source of stress for parents. Though parents did perceive some positive implications of their illness for their children, these seem to be outweighed by the number of concerns they report about the impact their illness has on their children and their credibility as parent. All three studies involved mothers, making it impossible to draw conclusions about gender differences in the experience of parental chronic illness. However, it seems likely that the concerns identified are more of an issue for mothers than for fathers since, despite changes in attitudes, mothers are generally expected to take the major responsibility for child care. At present, it is also unclear whether the concerns that emerge from these studies apply to parents with IBD.

Finally, while the findings highlight a possible need for practical and emotional support for parents with a chronic illness in order to reduce stress, it would be unwise to draw any conclusions from this work about the *ability* of people with chronic illnesses to parent. A small scale study aimed at developing a measure to assess performance of parenting tasks found that there was no association between parents' perceived competence in meeting the demands of parenting and actual performance (Nehring *et al.*, 1995).

1.5 THE IMPACT OF PARENTAL ILLNESS ON CHILDREN

In this section, we look at whether there is any evidence to support either parents' concerns or positive perceptions about the impact of parental chronic illness on children. The growing

interest in the impact of parental chronic illness on children is reflected in the number of recent reviews of the literature (Kahle and Jones, 1999; Korneluk and Lee, 1998; Armistead *et al.*, 1995; Kelley *et al.*, 1997; Roy, 1990). All reviewers have suggested that it is too early to draw firm conclusions as to the impact of parental illness since relatively few studies have been carried out in this area and many that are available have been criticised on methodological grounds. Research on children falls into two broad categories: qualitative research looking at children's experiences, which gives us an insight into how children perceive themselves as being affected by their parent's illness; and quantitative studies, which use measures of child adjustment as an indication of the extent to which parental illness impacts on the child.

1.5.1 Research on children's experiences

Studies in which children have been asked about their experiences in living with a parent with a chronic illness are very rare. In reviewing the literature, we have identified three studies which have involved in depth qualitative work with children, one concerned with rheumatoid arthritis and two with cancer.

In the study described earlier in this review, on the experiences of families in which a parent had rheumatoid arthritis, interviews were carried out with 40 children drawn from 22 families (le Gallez, 1993). Many of the children involved in the study were adults at the time of interview and it is not clear whether they were asked to describe their current situation or whether retrospective data were gathered. However, given the limited amount of research in this area it is worth considering the findings.

Le Gallez reports that 75 per cent of the children felt that it had not been detrimental to them to have a parent with rheumatoid arthritis. They continued with their everyday life without much disruption, taking on only housework, shopping responsibilities, and minor personal care responsibilities. The 25 per cent who felt having an ill parent had been detrimental to them were said to split into two groups: those whose parent had been unable to accept the pain and physical limitations; and those children who resented the fact that their parent was ill. It is not clear how the author arrives at this finding. The author also found that most children were extremely aware of the pain and suffering experienced by their parent and 'displayed a nurturing attitude to the ill parent'. Half felt this had brought them closer together as family. Seventy-two per cent of the children were afraid of developing the disease but had not discussed this with their parents. In terms of support from professionals, both children and the partners of the ill parent requested that they be given more opportunity to be involved in the patient's care and treatment. Again these findings must be treated with caution since it is unclear to which age range of children they apply.

Rosenfield (1983) carried out interviews with eight daughters (aged 12-20 years) of women who had mastectomies two to three years before. The daughters reported being under most stress during periods when their mother was in hospital and undergoing chemotherapy. Half of those interviewed were worried that their mother would die and most also worried about whether they too would suffer from the disease. However, they did not discuss these fear with others. Most felt they had not been given sufficient information about the cause and inheritability of breast cancer.

A pilot study of 24 adolescents (16 sons, eight daughters) whose parents had been diagnosed with cancer two to six years previously, involving in depth qualitative research, found that the adolescents felt that their parent's cancer had restricted sports and leisure activities; increased their involvement in domestic responsibilities; and altered relationships in some cases (Nelson *et al.*, 1994). Only some of the sons felt that increased household responsibility was problematic. Changes in relationships with the ill parent were reported to be positive, with the illness bringing the child and parent closer together. Seven of children reported that their fathers, who were the partners of the ill parent, had become irritable, anxious and depressed. In four cases, this was said to have caused a deterioration in the child's relationship with the father. Problems with school life, such as keeping up with school work and attendance, were predominantly reported by boys. For sons, having the opportunity to spend time out of the family home with friends was reported to be helpful, enabling them to forget about the parent's illness for a time.

1.5.2 Research on children's adjustment

The research that has been carried out to assess the extent to which children are affected by parental chronic illness has covered a range of conditions. These include cancer, chronic pain, diabetes, hemophilia, Huntington's disease, HIV, rheumatoid arthritis, spinal cord injuries, tuberculosis, multiple sclerosis, and myocardial infraction. The work on cancer is often concerned with the acute phase of the condition, shortly after diagnosis. Since the challenges faced by these families are different from those in which a parent has IBD, it would be inappropriate to draw any conclusions with regard to parental IBD from such work.

Much of the research in this field suffers from a number of methodological flaws. Sample sizes are often small, many studies lack a control group, measurement instruments are sometimes unreliable, and retrospective designs have often been employed. In recent years, researchers involved in this field of investigation have also been criticised for tending to search for problems in children, measuring only symptomatology and difficulties, without considering well-being and competence (Blackford, 1999; Kahle and Jones, 1999; Korneluk and Lee, 1998). Similarly the mechanisms investigated tend to be negative, for example disrupted parenting and marital discord, providing clinicians and families with little advice on how best to support children (Korneluk and Lee, 1998).

Overall, the research to date suggests that while children may be distressed by their parent's illness, they are not at risk of psychosocial problems which are in the clinical range of severity (Kahle and Jones, 1999; Korneluk and Lee, 1998). However, caution is needed in generalising these findings to children of parents with IBD since the conditions investigated are somewhat dissimilar. In particular, the unpredictability, social stigma and isolation experienced by parents with IBD may not be shared by parents in other groups.

It is important to note that the findings vary considerably depending on whether measures of children's adjustment are based on the child's self report or reports by adults, such as parents or clinicians. When data are based on children's self-reports, research which has compared children who have chronically ill parents with control groups, has found elevated levels of anxiety or depression, although most children do not score in the clinical range. This is different from research based on parents' and clinicians' assessments, where findings are less consistent. Studies involving parents recently diagnosed with cancer, and those with rheumatoid arthritis and hemophilia, have found no problems in children's psychosocial adjustment. In contrast to this, problems are reported in studies of mothers with HIV, parents with terminal cancer and chronic headache sufferers. A disparity between children's and adults' reports has also been found in research comparing different chronic illnesses. The hypothesized severity effects of different conditions (in one study breast cancer was hypothesized to be more severe than diabetes and fibrocystic breast disease, in another chronic pain was considered more severe than diabetes) have only been found in reports from children and not in reports from parents or outside observers (Korneluk and Lee, 1998).

Discrepancies between parents' and children's reports are not surprising as the general literature on response to measures of emotional and behavioural difficulties has found that children tend to report internalizing problems more frequently than their parents (Achenbach, 1991). Reviewers also suggest that the findings may reflect a child's desire to conceal problems from the ill parents for fear of causing upset (Korneluk and Lee, 1998).

Factors which influence children's adjustment

Many of the studies carried out to examine the impact of parental chronic illness on children have employed 'within' subject designs, in which factors hypothesized to contribute to the variability in the way children respond to the illness are investigated. In this section, we review this research evidence to identify the factors which protect or put children at risk of adjustment problems. The factors which have received research attention include demographic variables, the parent's adjustment to the illness, marital discord, coping strategies, and resources available to the child.

Demographic factors

Four studies have focused on age and gender differences in children's adjustment. All have involved children exposed to cancer. Three of the studies found that adolescents were at greatest risk of developing psychosocial difficulties (Grant and Compas 1995; Compas *et al.*, 1994; Howes *et al.*, 1994). Two of these studies report that girls whose mothers have cancer are at greater risk than boys (Compas *et al.*, 1996; Howes *et al.*, 1994). Grant and Compas (1995) provide some evidence as to why this might be happening, finding that adolescent girls report more strain from household responsibilities. However, a recent study carried out in the UK of children aged eight to 16 years produced findings inconsistent with this general trend, with adolescent boys at greater risk of adjustment problems than adolescent girls (Nelson, 1999).

The parent's adjustment to the illness

Evidence is beginning to emerge that the adjustment of the both the ill and non-ill parent to the illness plays an important role in mediating the impact of parental illness on children, with three studies on different chronic illnesses reporting an association. In a study of parents with cancer, an association between parental and child adjustment was found (Nelson, 1999). In families in which a father had hemophilia, associations were found between depression in either the ill or non-ill parent and the child's internalizing problems as reported by the mother, father and child (Steele, *et al.*, 1997). Further analysis of data collected from the same sample indicated that increased distress in the father was associated with more depressive symptoms, but not more anxiety, in children. Finally, in a study of patients suffering from chronic pain, emotional distress was found to be positively associated with children's somatic symptoms (Jamison and Walker, 1992). The latter study has been criticised for relying on patients' reports for the measurement of child variables since their distress may skew perceptions of the child's behaviour (Armistead *et al.*, 1995).

Marital discord

The limited research on marital conflict within the family has produced contradictory findings. Whereas Lewis *et al.* (1989) found a link between marital satisfaction and child adjustment in families where the mother had breast cancer, diabetes or fibrocystic breast disease, Steele *et al.* (1997) found no link between marital discord and child difficulties in families with hemophilia. It has been suggested that these findings reflect differences in the measures used to assess the marital relationship, with children only being affected by marital conflict which impacts directly on them (Korneluck and Lee, 1998). However, the study by Lewis *et al.*, has also been criticised for relying on fathers' reports, as it may be that marital dissatisfaction and depression cause parental perceptions of poor psychosocial functioning in children (Kahle and Jones, 1999).

Coping strategies

Research into the coping strategies used by children has been carried out in relation to parents with cancer and hemophilia (Steele *et al.*, 1997a; Compas *et al.*, 1996; Kotchick *et al.*, 1996). Results indicate that use of emotion-focused strategies, particularly avoidant coping strategies, is associated with poorer adjustment. This research has been criticised for two reasons, for assessing children's general coping style, rather than examining how children cope with the different types of stressors associated with parental chronic illness, and for not examining developmental differences in the way that children cope (Korneluk and Lee, 1998).

Two of the studies mentioned above also investigated the role of parents' coping and found that avoidant coping, by either the ill or well parent, was associated with increased parental reports of internalizing or externalizing problems in the child (Steele, 1997a; Kotchick *et al.*, 1996).

Uncertainty about illness

As outlined previously, the family systems-illness model proposes that uncertainty about illness trajectory places a strain on families. One study, involving 65 families in which a father had hemophilia and half were also HIV positive, examined the relationship between uncertainty and children's internalizing problems (Steele *et al.*, 1997b). Each family member completed the Mischel Uncertainty of Illness Scale (MUIS), which assesses uncertainty with regard to symptomatology, diagnosis, treatment, relationship with caregivers, and planning for the future. The MUIS has two sub-scales: ambiguity and unpredictability. Only the ambiguity sub-scale was used in this study since it has been found to be more reliable. Both child and parent reports of internalizing problems were collected. Regression analysis revealed that objective measures of illness severity and father's ratings of ambiguity were not predictive of the child's adjustment. However, children's ambiguity scores did predict the child's response to the Child Depression Inventory (CDI) and the Revised Children's Manifest Anxiety Scale (RCMAS). Furthermore, the mother's ambiguity accounted for an additional proportion of the variance in the child's self-reporting of anxiety. The mechanism by which mother's uncertainty affects child adjustment is unclear, but the authors hypothesize that it interferes with the mother's parenting. They conclude that future research examining the impact of parent illness on child adjustment needs to move beyond objective measures of the illness, to assess family members' subjective response to the illness. They also suggest that parents give children developmentally appropriate information about their illness as this may reduce children's uncertainty.

Resources available to the child

According to theories of stress and coping, just as the way in which parents' appraisal and coping with chronic illness will depend on the resources they have available to them, so too will the child's response to the parents' illness. In this section, we review the limited amount of research examining the role of various resources. We begin with the resources that children themselves bring to the situation, before considering resources available within and outside the family.

Child resources: In recent years, studies have begun to examine the contribution that children themselves make to their own adjustment, examining the child's psychological and cognitive resources. For example, a preliminary study involving eight to 16 years olds whose mother had diabetes or arthritis found that children's self-esteem and positive perceptions of their mothers' illness were associated with better ratings on measures of children's psychosocial adjustment (Conrad and Hammen, 1993). In the same study, mothers' reports of the child's friendships and higher academic performance were also found to predict better adjustment in the children. This pattern of results was replicated in a larger scale study of children (n=80) whose parents had cancer, in which poor adjustment was associated with the child's negative appraisal of the parent's illness and low self esteem (Nelson, 1999). These findings support the hypothesis proposed by theories of stress and coping that the child's appraisal of parental illness determines whether it causes stress.

Family resources: The few studies which have looked at the social and financial resources available within the family have found associations between the child's adjustment and a range of variables. One study which did not find associations involved families in which the mother had either breast cancer, diabetes or fibrocystic breast cancer, and there were children aged between six and 12 years. The researchers reported no association between the child's psychosocial functioning and either social support or income (Lewis *et al.*, 1989). However, this was a small scale exploratory study of spouses' (n= 48) reports of family adjustment to chronic illness, and the authors point out that the sample was somewhat unusual. Spouses had relatively high levels of income, education and social networks. Thus lack of variability within the sample on these variables may explain the non-significant results.

Researchers have examined the influence of the child's relationship with the non-ill parent, since this person may be an important resource to the child, offering information, reassurance and social support. Two studies found that the quality of the child's relations with the non-ill parent was associated with the child's psychosocial adjustment (Lewis *et al.*, 1989; Steele, *et al.*, 1997). In a study of families in which a parent had cancer, the author reported that children

of single parent patients seemed to be more vulnerable than those in two parent families, but acknowledged that the number of single parents involved in the sample was small, making it difficult to come to a firm conclusion (Nelson, 1999).

One of the most recent studies has found associations between the child's adjustment and parenting by the ill parent (Dutra *et al.*, 2000). The study involved 82 families in which the mother was HIV positive and there was a child between 8 and 11 years of age. A number of family variables were investigated: family structure variables, maternal variables, and parenting variables. In the child they assessed 'resiliency'- a composite score based on measures of child and mother reported internalizing and externalizing problems, and mother-reported cognitive and social competence. Two parenting variables - monitoring outside the home and having routines within the home - were found to be associated with resiliency. However, the authors acknowledge that the significance of these variables may be linked to the environment in which project participants lived: a high risk urban neighbourhood.

Relationships within the family have also been given some attention by researchers, since it is hypothesised that children are more likely to be distressed if levels of communication are poor and they are unable to talk to their parents about their worries. However, in her study of families with cancer Nelson (1999) found no relationship between poor communication within the family, or lack of knowledge about the illness, and children's adjustment. In children of parents with rheumatoid arthritis, greater family cohesion and lower conflict was found to be associated with better child adjustment (Hirsch *et al.*, 1985).

Resources outside the family: Despite the fact that it would be useful to uncover factors outside of the family, such as the role of peers, schools and other services which may protect children experiencing parental illness from developing adjustment problems, this is an area which has not received attention. To our knowledge only one study has looked at such factors, finding that low psychosocial support from school was associated with adjustment problems (Nelson, 1999).

1.5.3 Reflections

While the qualitative data from parents and their children suggest that parental chronic illness may have some positive implications for children, such as children being more caring and better able to cope with everyday difficulties, there is no firm evidence to support this since few researchers have examined such variables. It is apparent, from the limited research evidence available, that the negative impact of parental chronic illness is greater when findings are based on consulting directly with children rather than adult proxies. However, it does not appear that children are experiencing problems in the clinical range of severity.

According to theories of stress and coping, parental chronic illness is only stressful to children if they appraise it as such, and this in turn will depend on whether the demands the illness places on the child tax the resources that they have available to them. There is a small amount of research to suggest that it is the child's appraisal of the illness, rather than the illness *per se*, which determines the child's adjustment. Since IBD has a highly unpredictable clinical course, the positive relationship, found by Steele and colleagues (1997a) between uncertainty about the ill parent's condition and child internalizing problems, is particularly pertinent.

At present it is too early to draw conclusions about the resources which may ameliorate the impact of the illness, since only a few studies have been carried out and these cover a wide range of variables. However, results are beginning to point the importance of the non-ill parent as a resource for the child. Further investigation is needed before it is clear what type of care and support is needed by the child from this parent. Since many families may not have such a parent available to them, further research is needed into the role of resources beyond the immediate family, including the wider family network, friends, and professional support. The fact that parents' adjustment to their condition has been shown to be a significant factor in a number of studies is also important, as it suggests that assisting parents in coping with their own, or their partner's condition, may in itself be beneficial to the children.

1.6 RATIONALE FOR THE STUDY

The research reviewed indicates that although some parents felt their chronic illness had been of some benefit for themselves and their child, in strengthening their relationship and fostering their child's compassionate nature, this was outweighed by the worries they had about the impact of their illness on family life. Theoretical frameworks suggest that the demands placed on the chronically ill parent by the child will differ according to the child's age. To date none of the studies on parents' experiences has directly addressed this issue, though such information is obviously vital if resources for parents are to be targeted effectively. The nature of IBD - its unpredictable course, the incapacitation it causes through symptoms such as pain and tiredness, along with the social stigma associated with many of the symptoms - suggests that parenting may be problematic for many patients with IBD. Despite this, no research has been carried out to investigate the experiences of parents with IBD or their need for support.

Research with children whose parents have other chronic illnesses suggests that parental IBD may have both positive and negative consequences for children. However, there is no research to date with the children of parents with IBD. Such information would be helpful in preparing patients for, and supporting them through, parenthood. If there are positive consequences for children, research evidence on this might be a source of reassurance for parents. Alternatively,

if there are potential difficulties, parents will be in a better position to deal with them if they know what to expect and are given advice on how best to respond. In reality, it is likely that the way in which children respond to parental IBD will vary. Research with children of parents with other chronic conditions has begun to identify factors which explain this variability, and in particular, to identify factors which may increase resiliency. These include: the adjustment of the ill and well parent; parents' coping style; communication within the family; psychosocial support in school; and the child's coping style, self-esteem, friendships, academic performance, and relationship with the well parent. Similar research with the children of parents with IBD would better equip professionals to offer advice to parents concerned about their children and how best to support them.

The aim of this study was to begin investigating this area by collecting in depth qualitative research data from parents with IBD. Issues investigated include the parents' perceptions of the effects of their condition on family life and their children, their ways of coping with these effects, and their need for support. Such research provides an insight into the impact of IBD on both parents and their children. Since it is inadvisable to rely on parents as a source of information about the *experiences* of children (Beresford, 1997), further research exploring this issue will be carried out with children at a later stage.

1.7 STRUCTURE OF THE REPORT

The remainder of this report is divided into three chapters. In the next chapter, we outline the research design and the methods employed in the study. Chapter Three details the research results. In the fourth and final chapter we discuss these results, reflecting on the strengths and limitations of the study, what the results suggest about the impact of parental IBD on parents and their children, and the implications for future research and practice, paying particular attention to the messages that have come out of the study for NACC.

CHAPTER TWO: RESEARCH DESIGN AND METHODS

2.1 INTRODUCTION

There were two major factors which guided the overall design of this study into the effects of parental IBD. First, this issue had not been investigated before. Secondly, previous research on the effects of other parental chronic illnesses has been criticised for having a negative bias, with researchers presupposing that parents and their children experience difficulties. We were keen in this study to avoid such a bias, giving participants an opportunity to describe their experiences, both positive and negative, in relation to parental IBD. Taking these factors into consideration, it was decided that an exploratory, qualitative research design should be adopted. Qualitative research produces data which is 'rich' or 'real', and it is now widely agreed that it is useful when the aim is to describe and understand a phenomenon. It also allows people to raise the issues that are important to them (Robson, 1998; Punch, 1998; Hakim, 1997). In the remainder of this chapter, we describe in detail the design and methods employed in this study, including the research sites, recruitment process, and the methods of data collection and analysis.

2.2 RESEARCH SITES

Two research sites, based on two NHS health trusts in the North of England, were involved in the study. Site A had a mostly urban population, with some rural areas. Site B was rural in character, with the population spread over a large geographical area. Both NHS trusts fell within the same health authority and had both hospital and community-based services. Within these sites, consultants in two gastroenterology clinics, and the organiser of a local NACC support group, were approached about the project and agreed to assist with the recruitment process. This ensured that both NACC and non-NACC members took part in the study. Approval for the study was secured from the local NHS research ethics committees in both sites.

2.3 THE RECRUITMENT PROCESS

As stated previously, the aim in qualitative research is to understand a phenomenon. Unlike quantitative research, which tries to represent statistically what is happening in the wider population, the sampling strategy does not need to be random. Instead, a strategy sometimes referred to as 'purposive sampling' is often adopted. This involves seeking out people to participate in the study who have the experiences the research is interested in investigating (Robson, 1998).

In this study, we were interested in investigating the experiences of parents with IBD. The criteria for inclusion in the study were that the person be a parent (mother or father) of a child aged between five and 16, and had been diagnosed as having IBD for at least one year. We intended to recruit up to 40 parents/couples to take part in the study.

In order to protect patient confidentiality, all potential participants were approached about the study through a third party. After seeking advice from staff in gastroenterology clinics, it was decided that a slightly different approach to recruitment should be taken in the two sites. In Site A, numerous strategies were used to recruit participants. First, it was agreed that a researcher would attend outpatient clinics to meet with potential participants face to face. During clinics, consultants and junior medical staff gave information leaflets about the study to all patients likely to have children. Those who were interested in taking part were then introduced to the researchers and given the opportunity to ask questions about the study. A researcher attended clinics for recruitment purposes on a regular basis for a six week period. Secondly, in a few instances where a consultant knew that a patient had children, the consultant wrote to them in person about the study. In addition, the local NACC support group was contacted about the project and agreed to send out information leaflets to all members thought to have children. The group was given 50 information leaflets to distribute.

In Site B, the gastroenterology clinic had a database which included the diagnosis, age and contact address of all patients attending their clinic. The nutrition nurse at the clinic offered to post out letters to all those who *might* have children, based on their age. A total of 40 letters were sent out, accompanied by a covering letter from one of the consultants at the clinic. The nutrition nurse, who was in regular contact with the local NACC support group, advised that it would not be worth sending information leaflets about the project out through the local group NACC support group since local members were likely to have received a letter through the gastroenterology clinic. However, some people living in Site B were members of the NACC support group in Site A and were recruited through this group.

The information leaflets (see Appendix 1) passed on to potential participants through the various methods outlined above, included a response form and pre-paid envelope. This enabled anyone interested in taking part in the study to pass their contact details to the research team. On receiving a response form, a member of the research team contacted the parent to discuss the study. At this point, anyone who met the inclusion criteria was invited to attend a focus group meeting.

At the outset it was intended that only parents of children aged five to 16 would be involved in

the study since pre-school children might be too young for parents to be able to ascertain the effects of their condition on the child. However, during the recruitment process a number of parents with children under the age of five expressed an interest in taking part. Furthermore, data collected during the first focus group with parents indicated that they felt there were important issues for parents with pre-school children which should be addressed within the study. We therefore decided to extend the study to include parents with pre-school children.

The response to the various recruitment strategies is given in Table 2.

Table 2: Recruitment of participants

Method of recruitment	Site A	Site B	Total
Researcher in clinic	9	0	9
Letter from consultant	4	6	10
Letter from NACC	2	2	4
Letter from consultant and NACC	1	0	1
Total	16	8	24

A total of 24 parents, representing different families, took part in the study: 16 from site A and eight from Site B. Although the response fell short of what was envisaged at the outset, it was deemed to be sufficient for this qualitative research study, as ‘saturation point’ was reached in the data, with no new themes emerging in the latter stages of the study (Ritchie and Spencer, 1994). It is unclear why there was a difference in response rate between the two sites. We had hoped that the database of names and addresses in site B would assist recruitment in this site. However, this was not the case. Instead, it seemed that face to face contact with a researcher encouraged parents to participate. Another possible factor is that, due to delays in ethics committee approval, letters were sent to parents in Site B during the summer holiday period.

A description of the sample, including their gender, age, family circumstances, employment and health, is reported in chapter three.

2.4 METHODS OF DATA COLLECTION

Our aim in collecting data from parents was to investigate: how IBD affected family life; what effects parents had noticed in their children; what strategies they used to cope with any

difficulties; and what recommendations they had about support for other parents. In designing the study, it was decided that focus groups would be used to gather this information since they provide research participants with the opportunity to share experiences and perceptions, which can lead to the formation of new ideas (Vaughan, *et al.*, 1996). This would be useful in developing recommendations about support for families.

Our intention was to hold separate focus groups for parents of children of primary and secondary school age since the issues of concern to these two groups parents were likely to be different. Neutral venues, away from hospital clinics, were used for all focus groups. In order to make attending a focus groups as convenient as possible for parents, the researchers held the meeting in the towns where patients attended outpatient clinics. This was near to home for most participants. Parents were offered a taxi to take them to and from the venue, payment of expenses, and the option of attending either a morning or evening meeting. Despite this, many parents found it difficult to attend a focus group. The main reasons given were family commitments and difficulties in leaving home because of poor health. In order to ensure we could include the views of parents unable to attend groups in the study, we decided to offer to interview them at home. Since the numbers able to attend a focus group were small, it was not possible to hold separate meetings for parents of primary and secondary school children.

Thirteen parents attended one of four focus group meetings (three in Site A, one in Site B). The number of parents present at any one group varied between three and five. In two cases, partners accompanied the parent with IBD to the focus group. A further 11 parents were interviewed at home, and in two instances a partner was present during the interview.

2.4.1 The format and content of the interview and focus group

Since the interviews were carried out simply as a means of giving people the opportunity to take part in the study, and not as a different form of data collection, the format and content of focus groups and interviews were kept as similar as possible. During the focus groups, two researchers were present throughout, taking it in turns to lead discussion of topics. All focus groups lasted two and a half hours, including time for refreshments at the beginning. Interviews varied in length, lasting between one to three hours.

Before beginning data collection, all participants completed a consent form (see Appendix 2). They were also were asked to complete a short questionnaire providing the researchers with some background information on their family circumstances and their health (see Appendix 3). Once this was complete, the focus group or interview could begin.

At the end of the focus group or interview, participants were thanked for their participation and given information about the timescale for completion of the project and how findings would be disseminated. They were also asked if they would complete a short questionnaire on their health (Appendix 4 - Short Inflammatory Bowel Disease Questionnaire (SIBDQ), Irvine et al., 1996) and return it to the researcher in a pre-paid envelope.

Further information on the focus group and interview topic guide, and the SIBDQ, are given below.

The topic guide for focus groups and interviews

The topics covered during both the focus group and interview were:

- the effects of IBD on everyday life
- how IBD affects you as a parent
- the effects you have noticed in your children
- ways of dealing with difficulties
- the support parents with IBD would like from services.

Parents were asked to think back retrospectively, reporting on experiences from the birth of their child to the present day. Those who had more than one child were asked to report on experiences with all children (see Appendix 5 for a copy of the focus group topic guide).

During the focus groups and the interviews, parents were given a number of tasks to assist them in thinking through the issues being addressed. First, they were asked to draw up a list of the three main ways in which IBD affects everyday life. Secondly, they were given a time line, on which were marked the different phases of a child's life: pre-school; primary school; and secondary school (see Appendix 6). At different points during the course of the focus group or interview, they were asked to make a note of how IBD affected them as parent, and the effects they had noticed in their children, on the time line. To encourage parents to think about both positive and negative experiences, they were given a red pen to write about positive experiences and a black pen to write about negative experiences. Finally, parents used a green pen to add to their time line any strategies used for coping with difficulties. In the focus groups, these tasks were used to facilitate discussion, with the researcher asking parents to discuss their list and time line at various points during the meeting. In the interview situation, the parent explained their list and time line to the researcher as s/he completed it.

The short inflammatory bowel disease questionnaire (SIBDQ)

The SIBDQ is a short version of the IBDQ, which assesses health related quality of life in

people with IBD. It was developed for use by practitioners in primary care and is estimated to take only five minutes to complete. The validity, reliability and responsiveness of the SIBDQ was assessed in 150 patients with CD and 45 with UC (Irvine *et al.*, 1996). It was found to explain 92 per cent of the variance in IBDQ scores in CD patients, and 90 per cent of the variance in patients with UC. It was also found to be reliable in patients with stable CD (test-retest reliability coefficient 0.65), and to detect changes in patients who relapsed. The SIBDQ is scored on a seven point scale, with 1 indicating poor health and 7 being optimum health.

2.5 ANALYSIS

Apart from on two occasions where interviewees requested not to be tape recorded, all focus groups and interviews were tape recorded and transcribed. When it was not possible to tape record an interview, the researcher took notes and wrote a report immediately afterwards.

Qualitative research produces a mass of data, and the analysis must follow a transparent, systematic and defensible process of reducing these data without losing a sense of their richness (Miles and Huberman, 1994). The 'framework approach' was used in this study (Ritchie and Spencer, 1994). First, in order to increase reliability, two researchers read all the transcripts from the focus groups to identify themes and agree a framework for allocating the data to a series of charts. The framework developed for this study consisted of both 'a priori' issues included in the topic guide, and 'emergent' issues raised by respondents. According to the framework approach, each chart is a matrix for displaying data on a particular theme. Each respondent is allocated a row, and sub-themes are organised in columns. Charts are useful in allowing themed data to be read both by respondent (by reading across the row) and by sub-theme for all respondents (by reading down a column). The work of charting was carried out by two researchers, one taking responsibility for interviews and the other for focus groups. After charting each transcript, the researcher checked the written materials (lists and time lines) produced by the participants. Any new data were added to the charts. The researcher charting the interviews also added any new sub-themes that had not been identified from transcripts of focus group discussions.

Data from the focus groups and interviews were charted separately since the analysis of focus groups and interviews are slightly different. In focus groups the intention is not to gather individual stories, but to exploit the dynamics of the group to facilitate group discussions. It follows that the unit of analysis is the group, rather than the individual respondent, and results are reported in these terms. Once completion of the charts, the focus group and interview data were compared. Since this revealed no differences in the substantive issues emerging from the two sources, it was decided that the interview and focus group data could be reported together. The following chapter reports the results which emerged from the study.

CHAPTER THREE: RESULTS

3.1 INTRODUCTION

In this chapter, we report on the data collected through questionnaires, focus groups and interviews. Data from questionnaires were used to provide a description of the health and family circumstances of participants in the study, and are reported first in this chapter. We then report on findings from focus groups and interviews. As described in the previous chapter, comparison of the data provided by focus groups and interviews revealed no difference in the issues being raised, so the findings are reported together.

The topic guide for focus group discussions and interviews covered: the impact of IBD on parents; any effects parents had noticed in their children; how they coped with being a parent and having IBD; and messages for service providers, including support received which has been useful and how parents would like to see services developed in the future. In this chapter we report parents' view on all these themes. In addition, a large number of participants chose to comment on support provided by NACC. These views are described in a separate section at the end of the chapter since such feedback may be useful to the organisation.

3.2 CHARACTERISTICS OF PARTICIPANTS

Five fathers and 19 mothers took part in study. Parents were aged between 26 and 54 years of age, with a mean age of 40 years. Half the sample were members of NACC. A breakdown of the sample by diagnosis is given in Table 3.

Table 3: Characteristics of the study sample: diagnosis and SIBDQ scores

Diagnosis	Number of participants	Mean SIBDQ score
CD	14	4.5
UC	8	5.4
CD and UC	1	2.5
Proctitis	1	6.2

The number of years participants had been experiencing symptoms of IBD varied between two and 36, with a mean of 15.1 years. The number of years patients had been diagnosed as having IBD varied between one and 36 years, with a mean of 14.2 years. Fourteen parents had undergone surgery because of their IBD and, at the time of the study, seven had an ileostomy.

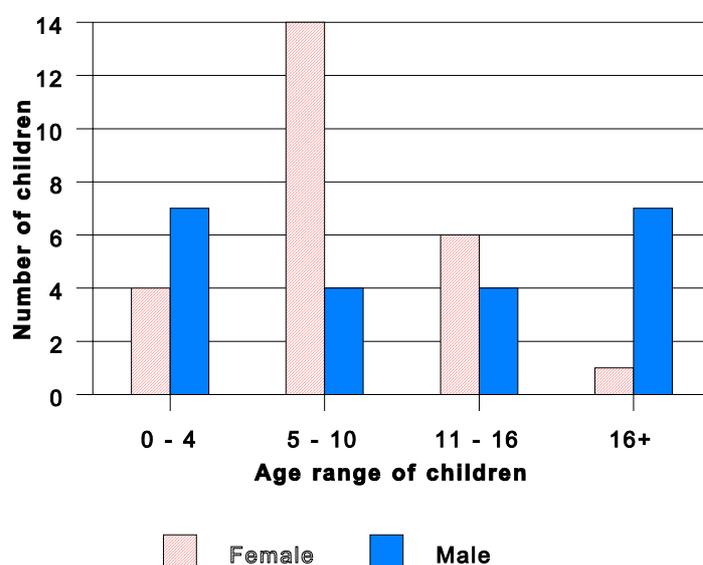
Twenty of the 24 participants completed and returned the SIBDQ. The mean SIBDQ score was 4.7 (1= poor quality of life, 7 = optimum health). The mean scores by IBD diagnosis are given in Table 1. These scores fall within the range and follow the general trend reported in other samples, with patients with CD scoring slightly lower on quality of life than those with UC (Irvine *et al.*, 1996). The mean SIBDQ scores for those with an ileostomy were slightly higher than for those without (mean SIBDQ with ileostomy = 5.7, without = 4.3). It is worth noting that two of the participants who did *not* complete the SIBDQ had an ileostomy, and another was a parent who felt her condition was very mild. Therefore, it may be that the SIBDQ scores slightly underestimate participants' quality of life.

At the time they took part in the study, most participants were living with a partner - only three were lone parents. In a few cases, this partner was not the parent of their child as the parents had separated. In terms of employment, eight were not working, nine were working part-time, and seven were working full-time. Of the five fathers in the study, three had given up work and one had taken part-time work because of ill health. One was employed full-time.

Parents had between one and four children each, with a mean of 1.96. Some children were not living with the parent, either because they were grown up and had left home, or due to the parents separating. The number of children living at home varied between one and three, with a mean of 1.67.

The age range of parents' children varied between under one year and 22 years, with a mean age of 9.6 years. The age and sex distribution of these children is shown in Figure 3. There were a total of 47 children in the families involved in the study.

Figure 3: Age and sex distribution of children whose parents took part in the study



3.3 THE EFFECT OF IBD ON PARENTS

Participants were asked about the positive and negative ways in which having IBD affected them as parents throughout their child's life. While many parents struggled to think of benefits for themselves as a parent, it was a great deal easier for them to think of negative effects. They reported negative effects on both their ability to undertake everyday parenting tasks and on their own emotional well being. However, it is important to acknowledge that even those who had experienced a lot of difficulty had positive things to say about being a parent. For instance, one parent who had experienced many difficulties as a parent with IBD pointed out that despite her experiences she felt she had made the right decision in having children because she adores them. Another mother who experienced a lot of difficulties with her health, including periods of depression following steroid treatment said:

If the sun's shining and I'm well, you know...that's absolutely marvellous and we really do make the most of it.

There was no difference in the negative effects experienced by patients with UC and CD. Instead, the effect IBD had on parents seemed to be influenced more by the severity of the parent's condition; and whether they were a mother or father.

First, in relation to the severity of the condition, parents explained that many of the practical difficulties they experienced in parenting were due to symptoms of the condition, such as incontinence, pain, tiredness and nausea. It followed that those with more severe conditions

experienced more negative effects as parents. Furthermore, those with a more severe condition were also likely to have experienced hospitalisation and treatment with steroids, both of which were reported to cause problems for some parents. Since having an ileostomy was reported to reduce symptoms such as incontinence, diarrhoea, pain and tiredness and the need for hospital and steroid treatment, it also appeared to reduce the negative effects experienced by parents.

Moving on to consider the second factor which influenced the impact of IBD on parents - whether the parent was a mother or father - overall it seemed that mothers reported more negative effects than fathers. This difference reflected the extent to which participants were involved in practical parenting tasks. For instance, while the pre-school years could be problematic for mothers because of the level of care and attention needed by children of this age, this was not such an issue for fathers. Although fathers did occasionally talk about it being hard to manage the care of young children, this was something most could hand over to the mother. Three of the fathers spoke of giving up or reducing work when their child was in nursery or primary school due to ill health and taking a greater caring role with their children. Under these circumstances, a few of the difficulties experienced by mothers were also experienced by fathers.

Aside from differences between individuals in the severity of the condition, the episodic nature of IBD also meant that the difficulties parents experienced changed over time. For instance, seven parents, including six mothers and one father, reported that their condition had deteriorated during the pregnancy or shortly after the birth of the child, and this was a particularly difficult period for these parents. However, two other mothers said their health had improved significantly during the pregnancy and some months after it.

In the remainder of this section, we go on to describe in more detail the positive and negative effects experienced.

3.3.1 Positive effects on parenting

As stated before, parents did have difficulty thinking of ways in which having IBD had been positive for them as parents. However, a number did speak about developing a closer relationship with their child as a result of their condition. As one explained:

'If you can talk about bowels you can talk about anything'.

Two of the fathers who had given up work because of poor health talked about having the opportunity to spend more time with their child. However, it should be noted that other fathers

who had given up or reduced work were more ambivalent, with one commenting that perhaps he had spent too much time with his child, and another perceiving the situation as largely negative because he had not wanted to give up work. Even a father who saw the additional time spent with his child as very positive spoke about initial difficulties in adjusting to his change in status to house husband.

A few parents pointed out ways in which having IBD improved their parenting. Most of these examples were related to health issues. For instance, being alert to the signs of IBD, thus ensuring that their child would be diagnosed quickly if s/he had the condition; being in a good position to know how best to support a child diagnosed with IBD; and being relaxed about children's health, aside from symptoms associated with IBD. Other benefits related to parenting included being more aware of a child's needs and more loving, and the family being forced to be flexible.

3.3.2 Negative effects on parenting

When describing negative effects, participants linked these to specific aspects of IBD which were stressful and caused them difficulties as parents. In this section, we look at each of these stressful aspects of IBD in turn and outline how they affected parenting. We begin with the stressors mentioned most frequently: incontinence and/or diarrhoea; and pain and tiredness. Then we turn to the stressors mentioned less frequently: nausea, hospitalisation; and steroid treatment.

- **Incontinence and/or diarrhoea**

Incontinence and diarrhoea was a major issue for parents. The impact was pervasive, affecting all aspects of their everyday life:

It really makes you aware of where you go, what you do, who you speak to, how long you spend... it controls every part of your life you know. It affects everything you do, the way you think, whether you're up half a dozen times of a night to the loo, it's embarrassing.

Parents attending one group explained that even when they were pain free, and therefore considered themselves relatively well, they might continue to suffer diarrhoea.

Parents of children of all ages spoke about incontinence restricting the family's social activities. For some, it took additional time to get to places because of the need to turn back in order to use the toilet. For others experiencing particularly severe flare-ups it could be difficult to leave the house at all. On leaving home, parents found it a struggle to travel. Some said they could not use public transport because of lack of toilet facilities, or that car journeys for any length of

time were problematic. A number of people said that incontinence restricted the type of activities they engaged in, and places they went, because of needing to be near a toilet. As a result family holidays, day trips and other social activities were limited to some extent. For instance, some went on holidays but found the experience stressful, others spoke of cancelling holidays at the last minute, and some chose not to go on holidays at all. Visits to other people's homes were also sometimes curtailed because of concerns about leaving unpleasant smells in toilets. Finally in relation to social activities, parents spoke about not being able to plan events or activities with their children because they were never sure whether they would be well enough to carry them out.

In addition to these difficulties experienced by parents with children of all ages, incontinence created specific problems for parents with children in different age ranges. The struggle involved in caring for babies and pre-school children, including feeding, bathing, and dressing young child, while suffering from incontinence was described by a number of mothers. They spoke of having to feed their baby while sitting on the toilet and being unable to leave the bathroom in order to attend to children who were crying. The following extract illustrates the distress this could cause for mothers:

You go to the toilet, and what do you do, do you put the baby down, you can hear the baby screaming the place down, you're rushing to the loo. I didn't want to go out and my husband would find that if he walked her for hours in the pram she'd stop crying and the terror for me was I couldn't walk far with the pram. I couldn't go to the shops. I did walk into town knowing there's a disabled loo. I'd get to them and then I had to give the baby to a complete stranger whilst I made it to the toilet all the while thinking, will I come back to find the baby there? And they're just looking at me, you know, mad woman. And I had nowhere to go to talk about this. ...I just couldn't deal with it. ...I remember my mother-in-law saying to me 'You don't have any feelings for this baby do you, will you hurt her?' And I said 'No I'd never hurt her'. But I felt nothing because to me I just couldn't deal with it.

Going on shopping trips was also an issue for parents of this age, with a number reporting instances where they had to leave their children, sometimes with strangers, in order to get to a toilet urgently. Some mothers spoke of being isolated because they would decline offers to go out with or meet up with other mothers for fear having an accident.

Once children reached school age, the impact of incontinence on parents altered. When the child began school a new set of parenting tasks was introduced. During the primary school years, a major focus of parents' attention was finding a way of getting their child to and from school during flare-ups. Mothers were also faced with invitations to get involved with school

activities and attend events which they sometimes felt unable to manage. Some mothers spoke of attending school events even though they found it extremely stressful, while others said they simply had to turn down such invitations even when the child wanted them to get involved. This problem also continued during the secondary school years. During the primary school years, expectations that the child would spend time with other children increased. However, at this age they were dependent on parents to facilitate this, taking them to and from other children's homes. In a few instances, parents spoke of their children only being able to socialise when other children came to their own home.

Some parents said incontinence became more embarrassing as the child got older and was aware of the parent having accidents and could ask questions. However, other parents reported that incontinence became less problematic, since the child understood the parent's need to be near a toilet and was less demanding.

Finally in relation to incontinence, it is worth mentioning that a number of parents felt that it was their fear of incontinence, as much as the symptoms, which limited their everyday life.

- **Pain, tiredness and nausea**

Pain and tiredness were symptoms of IBD which were usually talked about simultaneously since they tended to occur together. When experiencing pain, parents would often get little sleep at night. They might also be taking medication which caused them to feel more tired.

There were a number of overlaps between the impact that incontinence and pain and tiredness had on parenting. Pain and tiredness were also reported to limit the family's social life and the parent's ability to spend time with other children.

Pain and tiredness were reported to have a strong impact on the care of pre-school children, including having the energy needed to look after, play, and deal with the behaviour of pre and primary school children. They were also reported to affect a parent's ability to be affectionate with young children:

It was just a chore to me, even to nurse her..I'm laid in bed and even that's too much for me, you just lay there and you just don't want to do anything...So you can imagine, I mean a cuddle with your daughter is too much, which is horrendous.

On a more practical note, a couple of parents mentioned not having the energy for domestic activities such as cooking. Such practical difficulties were reported to be less of an issue for children of secondary school age since they were better able to fend for themselves and to help

the parent out with such tasks.

The main way in which pain and tiredness seemed to differ from incontinence was that these symptoms were said to be the main cause of irritability, reducing people's tolerance threshold, making them more short tempered and less able to deal with misbehaviour than they would otherwise be with young children.

A few parents who experienced nausea as a result of IBD spoke of the difficulty they had in preparing food for their children.

- **Hospitalisation**

For parents who had been hospitalised during the course of their child's life time, difficulties were mostly in relation to young children. First, parents described the difficulties associated with managing hospital visits. A number were concerned about young children seeing them very unwell or attached to machinery and tubes. For this reason hospital visits were sometimes limited. Mothers also reported some worry about how the family were managing at home. Most parents had someone at home who could care for the children in their absence. However, in two cases where such support was not available, social services were contacted, and it was suggested that children be placed in care. Parents found this very distressing. Returning home after hospitalisation was also problematic for parents, since it was difficult to care for children when you had not fully recovered. One father involved in the study had spent most of the first year of his child's life in hospital. Both he and his wife felt this had caused difficulties in bonding between him and the child.

- **Steroids**

A few of the parents who took part in the study reported adverse reactions to steroids, causing severe mood swings. This was reported to be very problematic since it meant difficulties in family relationships at a time when the parent needed family support. One mother who said steroids had induced clinical depression described this experience as more frightening than the IBD.

3.3.3 Negative emotions experienced by parents with IBD

During the course of the focus group discussions and interviews, parents described a number of negative emotions experienced as a result of having IBD and being a parent. The most frequently reported emotion was worry or fear. The majority of these fears were either about managing incontinence or about the condition being hereditary.

In relation to incontinence, parents spoke about the fear of having an accident while taking their child to school, of being scared to go out for fear of losing their dignity, and of being exhausted by going on holidays because of the amount of time spent worrying. In one focus group, mothers discussed the possibility that wearing incontinence pads might be helpful, but all agreed that they could not bring themselves to do this because of concerns about their visibility and unpleasant smells.

Concerns about whether the condition was hereditary were expressed both by parents whose child had suffered some bowel problems and by those who had not. A number of parents reported worrying when their children had occasional bouts of diarrhoea. There were also two parents whose children were having frequent bouts. In this situation, the parents were unsure how to respond, uncertain as to whether their child was genuinely ill or simply copying them. Both had discussed the issue with their consultant. This following extract outlines how the symptoms had developed in her child and the dilemma for the parent in knowing how to respond:

She's always been very aware and any literature there was about it, she's been, you know, reading it since she was five. She probably knows more about this than I do by now and she's seen the scares on television about the measles vaccine and what have you. She takes it in and she's aware of the implications of these things and she says : 'But I had that vaccination, does that mean I'm going to get it Mummy?' Now suddenly she's started getting a lot of tummy aches. Now she's under the hospital, they haven't ruled out Crohn's but they haven't said it, you know, they won't tell me one way or the other. Like I said at the moment there are lots of possibilities for her and one of them is she is putting it on for attention because when Mummy is poorly, Mummy gets to go to bed. Suddenly tummy aches appear when she doesn't want to go to school or she doesn't want to do something, but how can you rule out whether it is something truthful or not?...I can't turn around and say 'Oh you're just making that up, you know, it's just you don't want to do something.' I always have to sit there and think well she could be genuine.

Other worries reported less frequently by parents were about the side effects of medication on the baby; the possibility that scars will burst during pregnancy; the child's perception of the ill parent; not being able to cope with child care if hospitalised; and not living long enough to see children grow up.

Mothers spoke of periods when they had felt depressed. Depression was attributed to a number of different causes: effects of steroids; the combined pressures of being a new mother and having the condition; discovering that you have an incurable condition; and time spent apart from her children due to hospitalisation.

Comments from a few parents suggested that missing out on the family activities was a source of upset for them as well as for their child:

When its all over (flare-up) you sort of sit back and think 'God, what have I missed out on'....I know you've probably got them for a long time but it's this time of their life that everything's happening, everything is ticking on and they're learning to walk, they're learning to talk, they're forming their opinions, you know.

A couple of mothers spoke about feelings of guilt due to the restrictions the condition placed on family life or not being able to attend school events. A few mothers who had difficulty managing when their children were babies spoke of feeling that they had not been as maternal as they should have been. One mother reflected that she probably felt worse about the situation than her children.

3.4 EFFECTS NOTICED IN CHILDREN

During the focus groups and interviews we specifically asked parents to report both the positive and negative effects they had noticed in their children. Overall parents found this quite a hard task, and commented that it was particularly difficult to think of the positives. However, most parents reported a mixture of both positive and negative effects.

In a few cases, parents reported that they had noticed no effects in their children and put forward a variety of reasons as to why this should be. Two parents said it was because their condition was not severe, so their children's lives had not been greatly affected. One parent said she had gone to great efforts to ensure her child did not realise when she was poorly and not to burden him with information about IBD. A mother of pre-school children said they were simply too young (three years and under) at the time when she was most unwell for there to be a noticeable reaction. A parent of a teenage daughter noted that she had spent a lot of time with a relative, so the condition had little impact on her.

Responses from parents with more than one child indicated siblings varied considerably in how they reacted. One parent suggested that these differences simply reflected a difference in temperament, whereas other parents attributed variation to differences in age.

Parents talked about the changes they had observed in their children with age. However, the reports were fairly mixed. Most said their children were more patient, understanding and helpful as they got older. However, one parent said she had noticed a considerable increase in resentment during the primary school years, due to the children being more concerned about the

social restrictions. Another reported that her child had begun making hurtful comments on moving to secondary school.

In one group, parents discussed whether the effects of IBD are greater when it is the mother or father who is ill. They concluded that the effect was probably greater if a mother had IBD since when fathers are ill there is usually still a mother around to do the caring. They acknowledged that for the child a father having IBD might be problematic in that it might make the father irritable. However, this was considered to be a minor issue for children relative to whether or not there was someone available to care for them. One of the fathers interviewed also suggested that the condition would have a greater effect if a mother was the affected parent.

In the remainder of this section, we report the describe the positive and negative effects noticed in children in more detail.

3.4.1 Positive effects

In terms of the positive effects noticed in children, being caring was mentioned most frequently. This was described both in relation to the ill parent and to people more generally, particularly others who were ill. In relation to the ill parent, participants said they had noticed their children became more caring when the parent was unwell. This could take the form of practical help, such as looking for toilets, offering to do housework and watching over younger siblings. It also included supportive behaviours by the child, such as being more tolerant, adaptable, better behaved than usual, or comforting. One parent mentioned that her children encouraged her to do things she did not think she could manage. Three parents said that the older children encouraged their other children to behave or help out.

Its positive to see how caring our children can be, they can be playing up and suddenly be the nicest children you can imagine when you're not well.

and

I mean they come and hold my hand, even when I'm sat on the toilet..he's so funny cause he'll go 'Poo Mummy you stink' and I'm like 'cheers son' But he'll still come.

A few parents reported other positive effects. Some felt their children were more independent and better able to look after themselves than their peers might be or more mature, for example '*it makes them understand that's life*'. A few parents spoke of their children having developed closer relationships with family members, including the ill parent and other family members involved with child care, than they might otherwise have done. Another positive effect was that children would be able to recognise the signs of IBD in themselves.

3.4.2 Negative effects

When parents were asked if they had noticed any negative effects in their children, a wide range of issues was raised, including both negative effects in their children's everyday life and negative behaviours they had observed in response to IBD.

- **Negative effects on everyday life**

The effects on everyday life overlapped greatly with the difficulties participants reported they had with parenting as a result of IBD. The most commonly reported negative effect on children's everyday life was restrictions in their social activities: children had to spend more time at home than parents would have liked, which in turn reduced their level of contact with peers; social events could not be planned in advance; and when they did go out as a family they were restricted to places with toilet facilities. Other effects were that young children sometimes did not have a parent who had sufficient energy to play with them and older children often missed out on parents attending special events, such as sports days, football matches, and prize giving ceremonies.

Parents of young children thought it must be confusing to have a parent with continence problems when they were being taught not to have accidents. A few parents of primary and secondary school children thought it was embarrassing for their children to have 'smelly' parents, making it uncomfortable for them to have friends in the house.

Other negative effects attributed to IBD were: children looking out for public toilets on the parent's behalf; children being born prematurely; babies picking up on the mother's stress; and parents separating when this was attributed, at least in part, to a partner's inability to deal with the effects of the condition. Only one parent mentioned children being involved in domestic activities to any great extent, describing the situation as:

They almost run it between the three of them, run what goes on in the house.... they've taken over, we've swapped roles almost.

- **Negative reactions**

In terms of the way in which children reacted to a parent having IBD, the negative reaction most frequently noticed by parents was anxiety or worry. While some parents simply said they had noticed their child worrying or checking up on them when they were ill, a few said it led to their child crying, withdrawing or developing headaches, in one case accompanied by vomiting. One mother was able to describe the process she felt led to her daughter's anxiety and headaches:

If I'm not well then David [spouse] gets particularly anxious and it just goes out

into the family and she is a very sensitive girl and she just picks it up.... Me being ill... if you made a graph of it would she would be directly proportionally anxious and stroppy and attention seeking and just generally difficult, which makes the whole thing so much more difficult..... Mummy's her security and if Mummy's not well then that shakes everything up for her and that shakes Daddy and Daddy gets cross with daughter.

The most common cause of anxiety or worry seemed to be hospitalisation. Two parents said their children had developed a fear of hospitals, becoming upset when they had to visit. A few parents reported that their children had asked whether they would develop IBD, with one saying that her children seemed to worry about this when she was having flare-ups.

Other fears reported by parents included: a parent who said her four and five year old children refused to eat when she was too ill to eat because they thought it would make them ill. A single mother spoke of how her children had refused to stay away from home overnight for fear that she would become ill and need someone to call a doctor. Even now as teenagers and young adults, when she had a new partner, she felt they were 'clingy' and had missed out because of not wanting to leave her on her own.

A number of parents said their children had reacted with anger or frustration. In most instances, this anger was reported in pre-school or primary school aged children. Anger and frustration was directed at parents, and usually occurred when parents were unable to accompany children to school or when activities were restricted because of illness. One child was said to have directed his anger at his younger sister since his mother became ill after her birth, saying 'you were alright before she came along'. Mild misbehaviour, 'playing up', or 'attention seeking', when the parent was ill, in hospital, or on return from hospital, was also reported.

One teenager was said to have developed 'strange eating habits' as a result of being nagged to eat properly by the ill parent.

3.5 COPING STRATEGIES

By far the most commonly used coping strategy for dealing with the impact of IBD on parenting was social support, with only three people *not* mentioning turning to others for help.

3.5.1 Social support

Parents talked about support provided by partners, extended family, friends, neighbours and school staff. However, the type and amount of support provided by these groups differed. Family and partners were relied on most frequently and for the whole range of practical tasks

involved in caring for children: caring for babies, supervision of young children, taking children to and from school, accompanying them to special events, taking them out for the day, as well as general domestic duties, such as cooking and cleaning. Aside from practical help, a few parents also saw extended family as a source of emotional support for children, referring to a grandmother as someone the children could escape to who was sympathetic, and the grandfather as a reliable male figure for the son of a single mother.

A number of parents spoke of the emotional support they received from partners. They spoke of the importance of having someone who was understanding and not embarrassed to talk about IBD. One parent explained that this made her feel comfortable and relaxed, which in turn made her feel physically better. Partners could also encourage parents to 'to stay on top of it', not allowing the condition to get the better of them. It also meant parents had someone to talk to about any problems with their child.

The extent to which parents drew on partners and family was of course limited by availability. Three of our sample were single mothers and did not have a partner they could easily turn to. Many partners were working on a full time basis, so were simply not around during the day to assist.

One parent noted that it should not be assumed that partners would be helpful. Her ex-husband had resented her illness, so did not help the children deal with it and exacerbated the situation. In contrast to this, her new partner was understanding, tolerant and happy to take her children out when she was not able to. This seemed to have reduced the resentment in her children. Indeed, a few other parents reported unsupportive responses from partners, such as anger or simply not being able to cope with the restrictions IBD placed on life.

It was notable in this study that a large proportion of parents had extended family nearby, and many commented that they did not think they could have coped if this had not been the case. Those who did not have extended family had to rely more on their partner. Parents who had neither extended family nor a partner to turn to for practical or emotional support had particular difficulties. They spoke of how problematic it could be to get children to and from school, shop for food, arrange for children to play outside the home (for example, in the park, visiting friend's homes, going on day trips etc), and organise child care when they needed to go into hospital.

A very small number of people turned to friends and neighbours for help. A few parents explained that they would not turn to such people because they did not talk to friends or work colleagues about their condition, preferring to 'keep it within the family'. Two parents said they tried to limit the amount of help asked for from friends because they were aware that it could be wearing for them. Similarly, a parent who sometimes asked a neighbour to take her child to school only felt able to do so because it was on the neighbour's route and was not an inconvenience. The same parent had got

to know a neighbour with ME who had a young child. This had proved useful since they had been able to develop a reciprocal relationship, helping each other out when unwell.

Aside from practical help, friendships could have other benefits. One parent spoke about the huge difference meeting another young mother with IBD made to her life. Prior to this her concerns about needing to use the toilet frequently, and the embarrassment of unpleasant smells, had prevented her from inviting people into her home. She felt comfortable with this mother since she also had IBD. This friendship helped her to develop the confidence to make friends with other mothers, which she felt prevented her from becoming 'a recluse'.

A few parents of children in primary school had told school staff about their condition and spoke very positively about the benefits of having done so. The staff involved had been able to assist in a number of ways, such as finding people to take the child to and from school when the parent was too ill to do so, allowing the parent to park next to the school entrance to enable easier access to toilets, and allowing parents the use of toilets which were used infrequently. One parent said she felt more relaxed knowing that the staff understood that her child would be late some days and that her condition was no longer a taboo subject. As one parent commented:

Its amazing how helpful it is to talk to school.

3.5.2 Practical strategies

Participants took a number of practical steps to deal with difficulties they faced. Some were focussed on preventing problems arising. Others were strategies for coping with difficulties when they arose.

Preventative strategies

- **Controlling symptoms**

Parents spoke of the need to take extra care to avoid flare-ups when you have children. This included taking medication at the first sign of a flare-up, eating properly, trying to stay relaxed, keeping fit and preparing for going abroad by consulting with their GP. However, they also pointed out that some of the strategies you might usually use to deal with IBD, for example resting, were not possible when you had children to take care of. It was particularly difficult to rest with a young baby in the house, and one mother commented that it was not until after her child started school that she finally had the chance to recover from a very severe flare-up following his birth. One parent said he was forced to stop taking steroids because the mood swings associated with taking this medication were having such a negative effect on his family.

- **Having an ileostomy**

One mother, who found that her condition was having a substantial impact on her ability to care for her children, decided that the solution was to have an ileostomy:

I just couldn't cope any longer with the constant diarrhoea, having to lift the children off the toilet so I could go, couldn't go shopping, I just couldn't cope. ...and the children just couldn't understand and I decided enough was enough.

All seven parents who had an ileostomy spoke of the benefits in terms of regaining freedom and control over their everyday life, making it possible to enjoy spending time with their children without worrying about incontinence. They did point out that it had been a difficult decision to take and required additional planning for parents:

Just the operation, it was just the best thing I could ever have done. It was the most frightening thing and took an awful lot of thought. I mean I don't know why I suddenly, I just suddenly said right we'll do it but all those years that...it's been there offered to me but I never actually said 'We'll go with it'....we had to plan what we were going to do with the girls..and their days would be planned in advance before I went to hospital. We wrote everything out on who would be doing what.

In one focus group, mothers who had not had an ileostomy discussed the fact that it might give them a new lease of life, but there was general agreement that embarrassment of having one, and the impact it might have on their sex life, was enough to stop them pursuing it as an option.

- **Family planning**

In some cases, parents sought to minimise the difficulties they faced by either making a conscious decision not to have any more children, or by leaving a substantial gap between having children. One mother said that leaving a gap had proved successful since her elder child enjoyed helping out with the new baby.

- **Alleviating potential stress on other parent and child**

A few parents talked about members of the family taking separate holidays to give each other a rest. One parent spoke of making a conscious effort to organise days out for children on their own so that they do not miss out on things they want to do.

Coping with specific difficulties experienced by parents

Aside from more general strategies to reduce the number of difficulties encountered, parents also reported practical strategies for dealing with specific parenting difficulties such as getting children to school; coping with misbehaviour; alleviating potential stress on others within the family; and coping with children's anxiety. These are listed in Table 4.

Table 4: Practical strategies used to deal with parenting difficulties

<p>Coping with difficulties getting children to school</p> <ul style="list-style-type: none">▶ paid for taxis to take children to school▶ arranged school journeys between visits to the toilet▶ taught primary aged children to walk to school together▶ arranged for children to attend combined infant and junior schools, cutting down on travelling▶ had a number of places on route where you can stop to go to the toilet▶ got permission to park next to school entrance so can get to toilet quickly
<p>Coping with child's anxiety</p> <ul style="list-style-type: none">▶ reassured child that I'm going to be fine▶ when father was in hospital, mother involved child more in helping at home▶ persuaded health staff to allow parent to stay at home with child when they wanted to admit her prior to birth of second child▶ got appointment with doctor for son when had some bowel problems▶ planned in advance with children what they were going to do when parent was in hospital
<p>Coping with incontinence</p> <ul style="list-style-type: none">▶ used children as an excuse for getting access to toilets▶ blamed smells on baby's nappies▶ made sure I had spare clothes with me when travelling▶ covered car seats with plastic bags▶ had an extra toilet put into the house
<p>Coping with misbehaviour</p> <ul style="list-style-type: none">▶ bribery- a visit to toy shop with grandmother

3.5.3 Positive thinking

Parents spoke of various types of positive thinking which they used to cope with IBD, although only some of them were directly related to parenting *per se*. First, a number of people spoke about the importance of family jokes about the condition:

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.

They pointed out that these jokes were kept within the family, and would not be considered funny by their children in the presence of others.

A few people spoke of thinking positively about their situation, for example, being grateful that they did not have cancer, keeping a mental note of things they had achieved, being positive about having the opportunity to spend more time with children because they had to give up work. One person spoke of gaining confidence in other areas of life, for instance by working, and how this seemed to help her gain weight and generally improve. One person spoke of turning to her faith, believing that there was a reason for the situation, and in the benefits of prayer.

3.5.4 Passive strategies

Avoidance is commonly referred to as a passive coping strategy and it will be clear from the earlier description of the impact that IBD was having on parenting that many parents were avoiding a range of situations where there was the potential for suffering embarrassment. This included avoiding shopping trips, days out with the family or other parents, school events, and travel of any distance. Mothers in one group discussed at some length whether the situation might be helped by wearing incontinency pads, but said they would rather stay at home than take such action.

Avoidance of thinking about difficulties was mentioned by a couple of parents: one described how she resorted to this tactic when her children were having temper tantrums and she felt there was little she could do about the situation:

I stick my music on very loud cos it's generally loud enough so that no matter how loud the kids are shouting, you can't hear them...I literally just blank everything, you know, crawl into my own little world, into my dream and try and pretend, you know. I live, you know, I live in the fantasy that everything is alright, you know that I'm going to wake up tomorrow and be cured.

3.5.5 Stoicism

This was mentioned by a few people, who referred to the fact that in certain circumstances, particularly when children are involved, you have little option but to get on with life despite the pain and incontinence:

You've just to get on with it, you have to. I mean even if it means, you know, I mean I've like changed nappies while I've been sat on the toilet, you know, while I'm busy the bairn still needs taking care of and when he's toddling about. I mean he was 18 months when the second baby came along, it's like making sure they didn't fall down the stairs all while you're on the toilet, do you know what I mean? Everything, you've got to put it on the back burner, you really have. I mean no matter how much pain you are in or what is happening, it's a case of you're in your own home, you know, you can clean up any mess, any accidents that happen but your kids have got to come first.

3.5.6 Talking to children

We specifically asked parents whether talking to children about their condition was useful, since there is some speculation in the research literature that communication within the family is positive for the child. Parents varied in how much information they gave their children, with some saying they deliberately limited the information they gave to their children, through to those who made a conscious decision to keep their children well informed. Those who chose to limit the information often spoke of not wanting to worry the child. Others specified that their children were too young to understand. This included both children of pre and primary school

age. One mother reported changing her mind about the best approach, explaining that she had thought it best not to tell her child when she was going to hospital because it made her child very anxious. However, on a number of occasions her daughter had found out what was happening anyway, and as result the parent felt trying to protect her was counter productive. A number of parents spoke of taking the child's lead, telling them as much as they wanted to know. Even those who spoke of limiting information said they answered their child's questions.

I knew the kids had to deal with it because of the questions they kept asking. I could either be honest with them or tell them a fairy story and if anything, I've always wanted to be honest with them.

Only a few parents said they were very open with their child about their condition. Interestingly, the reasons given for doing this were generally the same as for those who limited information: to avoid worry. For instance, one explained:

If they didn't actually know there was a reason behind it [going to toilet, being poorly, irritable and in hospital], I think it would put, that would have quite an effect on the children.

All parents agreed that it was important to explain things at the level which the child understood. For many parents of younger children this meant that they never mentioned the words ulcerative colitis or Crohn's disease, but instead talked about having a 'poorly tummy'.

Although it was apparent that parents varied in whether they felt it was appropriate to talk to their children about IBD, those who had given information reported that on the whole it had been useful. It resulted in children being more helpful and understanding, they were aware why a parent was being irritable. However one parent said that, if anything, having a good understanding of the situation had increased her nine year old daughter's frustration and anger because she realized the condition was not going to go away.

Parents did point out that it could be difficult to explain many aspects of IBD to young children, particularly those under the age of five. They mentioned difficulties explaining ileostomies, being too tired to do things, equipment in hospital, why you are not allowed to eat while on a drip, and why you need to use a toilet so much.

Just as parents varied in how much information they gave their children, children were reported to differ in how much they wanted to know. For example, in one group a parent talked about her son having a morbid fascination with anything gruesome, so liking to talk about her condition, while another spoke about her daughter hating anything to do with blood and hospitals.

3.5.7 Unsuccessful strategies

We specifically asked people if there was anything they had tried to do to cope which had not been helpful. Just a few things were mentioned. First, a couple of people said they had not found the 'can't wait' cards, which are meant to enable speedy access to toilets, of any use. They reported that most shop assistants did not know what they were, and by the time they had managed to explain it was often too late. A couple of parents felt that steroid treatment was not helpful since, although it might help you physically, the effect on your mood could be detrimental to family relationships, pushing people away from you at the time when you needed them most. Finally, one parent reflecting on her attempts to manage by herself said:

Don't try to manage on your own...ask for help. You do have to ask, ometimes you feel belittled, but it's a good thing to ask for help.

3.6 SUPPORT FROM SERVICES

3.6.1 Useful support received

Parents spoke about useful support received from health and education services, as well as from employers.

Health services

In relation to health services, the support mentioned most frequently was the parent's relationship with staff providing medical care, including consultants, GPs, and stoma nurses. Parents valued staff who they could talk to about their condition; who understood the family situation; helped them prepare for important events in their life, such as holidays and school outings; were easy to contact; and respected their views on altering medication or having treatment. When such support was provided, parents spoke in glowing terms about staff. For example:

My consultant is wonderful - I can talk to him about anything

Support before and after the birth of a child was important to mothers who experienced difficulties during this time. One mother appreciated her consultant visiting her on a regular basis, understanding that she was very concerned about the effect of steroids on the baby and being supportive throughout. Another parent was pleased to find that her midwife was knowledgeable about IBD. Useful support following the birth included a midwife who spotted a mother who was depressed and intervened to offer support, plus a health visitor who organised for a mother to get child care assistance from a student at a local college.

Being put in touch with others who have IBD was valued, particularly when it was someone in a similar situation to the parent, that is, someone with children. In all but one case, this was

arranged to help prepare people for having an ileostomy. It was reported to have reassured people because it allowed them to discuss anxieties about what the ileostomy would look like, how to deal with sex, and whether it was alright to get pregnant:

The surgeon was able to ask this couple and his kids to come around and have a talk with us one evening about it (having ileostomy) and that just took a whole weight off my wife because they came and discussed the benefits, the situation of the bags, how you deal with sex, all sorts of issues that you wouldn't normally talk about and it was, well I couldn't wait to have it done. If I hadn't had that family to come and talk, well I was petrified.

A few parents who had experienced considerable delays in obtaining a diagnosis stressed that once they had a diagnosis life was a great deal easier. It made it possible for them to talk to others about their health, it increased their confidence because people no longer thought they were simply lazy or not bothered about their children, and made it possible to seek advice.

Education services

As described previously in relation to how people coped, useful support provided by schools included:

- ▶ to be allowed to park next to school
- ▶ to have access to toilets not used frequently
- ▶ to understand that their child might sometimes be late
- ▶ to assist in getting the child to and from school when the mother was not able to do this.

Employers

One parent who had been a member of the armed forces said they provided summer camps for his daughter and a period of convalescence for him every year. Both were reported to give the whole family a rest. Another family reported that the employers of the partner who was well were very helpful, allowing her to have time off work to care for their child when the father was in hospital. A single parent was grateful to the head teacher of a local school for offering her a part time job. This increased her confidence, which seemed to improve her health.

3.6.2 Support needed by parents

Parents wanted four types of support: practical assistance; information for themselves; awareness raising and publicity about the condition; and support in coping with the condition.

Practical assistance

- **A crisis support service**

A large number of participants felt that parents with IBD would find it helpful to be offered

practical assistance with the following:

- ▶ getting children to and from school
- ▶ shopping
- ▶ housework
- ▶ cooking.

Since problems arose irregularly, depending on the fluctuations in parents' health, it was concluded that a crisis support service needed to be set up. Parents stressed that such a service was very important as a preventative measure, since otherwise families will only receive support after the family has run into major difficulties. They recognised that many people would not need such a service since they would have family members who provided such support. The service should therefore be targeted at single parents and those without family living nearby. The service would be especially useful to those with young children.

It was considered important that such a service be able to assist at times when parents were hospitalised, particularly when the parent did not have a partner or family to support them. This might help prevent children facing the trauma of being placed with a foster family. Whoever provides such a service should also know enough about IBD to be able to explain to the child what was happening if their parent had to be rushed into hospital.

Even those who had family who could provide support, said it would be useful to have a helpline, who could contact family members on their behalf in times of emergency, since it was often difficult to manage this when very ill and by yourself.

- **A system for reducing prescription costs**

Parents said they were spending a substantial amount of money on prescriptions when they were having flare-ups, often needing to obtain repeat prescriptions every seven to ten days when they were having a flare-up. This was a burden when many parents were unable to work full time because of ill health, and it reduced the financial resources available to the family.

- **Developments in medical services**

Suggestions included:

- ▶ somewhere for patients to convalesce away from the family
- ▶ facilities for home treatment so that parents do not have to go into hospital when having bowel rest and tube feeding
- ▶ wards specifically for IBD sufferers where they can go when brought in for tube feeding.

- **Support from social services and housing services**

Parents spoke of the difficulty getting social and housing services to recognise their needs. They asked for easier access to disabled parking, to make it easier to get to toilets in time, thus enabling them to be less worried about taking their children out. They also felt that housing services need to be more aware of the importance of providing families in which a person has IBD with homes which have more than one toilet.

Information for parents

Parents specified that they needed information and advice on:

- the effects of IBD on pregnancy and family life
- ileostomies
- what to expect on leaving hospital after surgery.

They also spoke about the way in which information was delivered by health staff, requesting that they be less clinical, more sympathetic, and take care about making insensitive comments about incontinence.

Awareness raising about IBD

Parents said awareness raising about IBD is needed with a number of different groups of people. First, generic health staff, including general nurses, health visitors and GPs, need to have a greater understanding of IBD. This might help to prevent problems such as difficulties obtaining access to toilets when in hospital, staff being unsympathetic, and GPs refusing to make home visits. Secondly, more awareness raising about the condition directed at retail companies might prevent people with IBD getting such a negative response when they requesting access to toilets in shops. Finally, parents suggested that it would be helpful if someone was to go in to schools to talk to teachers and pupils about IBD. One of the messages they wanted communicated was that the IBD is not infectious.

Support in coping with the condition

Parents spoke of wanting support in coping with the condition, both for themselves and for their partners.

- **Support for the parent with IBD**

In relation to support for themselves, parents highlighted a number of areas where improvements could be made. First, as mentioned previously they felt that generic health care staff could be more supportive towards patients with IBD. This might make it possible for parents to talk about their situation with staff they come into contact with regularly, such as

health visitors.

Secondly, many parents felt that health services for patients with IBD were too focussed on medical interventions, and asked that consultants consider the family situation when arranging treatment. Parents spoke of wanting advice for themselves on taking control of the condition; stress management; how to deal with sex; and simply having someone to talk to. They felt that a key time for offering such support was after the birth of a child. This could take a number of forms, such as a helpline, health visitors or midwives following up on mothers at home, or the setting up of a network of parents. The model of nurse specialist, said to already be in place in an area outside the study sites, was cited as good practice. This nurse sees people in clinics, with their children if they wish, offers advice on pregnancy and sex, and runs a 24 hour helpline.

- **Support for partners**

A number of parents felt that counselling and advice should be offered to partners, particularly after having an ileostomy, since a few partners were reported to have reacted badly to IBD. It was suggested that it might be useful if this took the form of a support group where partners could get together on their own without the person with IBD being present. One of the partners who took part in the study reflected on the fact that she had been given no information about IBD when her husband was diagnosed. At the very least she felt should have been offered information leaflets and details of support groups.

Support needed by children

Parents found it more difficult to think of support that should be offered to children. However, they suggested two things:

- **Information for children**

Parents said that it would be very useful to have a book or leaflet written for children which explained IBD. Rather than focussing on what IBD is, it should explain how it affects parents and their children in everyday life. It should also help answer difficult questions which children sometimes put to parents such as 'will you die?'. This book could be used by parents to talk about IBD with their children. It would also be useful to have leaflets for parents advising them on what to say to their children about IBD.

- **An opportunity to meet other children whose parents have IBD**

Parents thought children might find it useful to meet other children whose parents have the condition. This would make them more aware that there are other families with similar problems, that both mothers and fathers get the illness, and they would have someone to laugh

with about the situation. One parent spoke of her daughter's excitement and pleasure at meeting another child whose mother had IBD. On this occasion, the meeting had happened by chance because one child had mentioned it to the other. Reflecting on her daughter's reaction, this mother could see how it would be beneficial for other children to have the opportunity to talk to each other. Parents agreed that such meetings should not be forced on children, but only happen if the child wanted it.

3.7 VIEWS ON SUPPORT PROVIDED BY NACC

Although we did not ask parents for their views on the support offered by NACC, parents discussed this during the course of the focus group and interviews. There were a number of things that parents had found useful: a leaflet produced about pregnancy (although only one parent mentioned seeing this leaflet); the newsletter, since it was comforting to know there were other families going through the same experience; and being put in touch with someone you could talk to on a one to one basis.

However, a number of people had attended their local support group and not found it very useful. A few had previously been members of NACC but had not renewed their membership as they felt that the local group did not meet their needs. There were a number of concerns about the local groups. Parents said they wanted to meet people of a similar age range who had families, but found that the groups tended to be attended by older people with whom they had little in common. In addition, they mentioned that the meetings seemed to focus largely on fund raising, and parents found it strange to be asked for money from a group which they were going to for support.

Similar complaints were made about the Ileostomy Association meetings: parents said the age range was too old and they had little in common with those who attended. They also mentioned feeling uncomfortable looking at ileostomy appliances with other people present, and did not like discussions where people ended up telling horror stories about their experiences, or where people played the 'hero', talking about things like running the marathon.

Parents made a number of suggestions about how they would like to see NACC developed in the future. First, they would like NACC to take an holistic view of the condition, realise that the whole family is affected by the condition, and provide opportunities for families to meet and have fun together. Secondly, a national helpline was suggested, which people could ring for advice and to be put in touch with other people in the local area who have IBD and a family. It was suggested that there was a role for the local groups in getting involved in offering practical help to people, though parents pointed out that this might be difficult with the current membership since people involved usually have the illness. Finally, it was recommended that NACC consider developing a more attractive, welcoming and fun image to encourage families to get involved.

CHAPTER FOUR: DISCUSSION

4.1 INTRODUCTION

In the final chapter of this report, we begin by reflecting on the overall strengths and limitations of the study, discussing both the research design and methods. Having considered this, we go on to discuss the findings: what they suggest about the impact of IBD on parents and their children; how they add to the existing research literature on parental chronic illness; and how they fit with the theoretical frameworks which guided the study. Finally, we consider the implications of the research findings for practice, including both public sector providers such as health, education, and social services, and voluntary organisations such as NACC.

4.2 THE STRENGTHS AND LIMITATIONS OF THE STUDY

This study represents the first investigation into the impact of IBD on patients in their parenting role and on their children. As there is no previous research in this field, it was appropriate to carry out a small scale exploratory study. A major strength of this study is that, by adopting a qualitative approach, parents were given an opportunity to provide an account of their experiences, without researchers presupposing what these might be. Adopting a qualitative approach has also enabled us to collect in depth data, providing an insight into some of the factors which influence the effect of IBD on parents and their children. Finally, aside from increasing our understanding of what life can be like for parents with IBD and their children, this study has given parents the opportunity to express their views on the types of support they would welcome from service providers.

Although this study is an important first step in understanding parental IBD, there are limitations to the conclusions which can be drawn from the findings. This was a small scale study involving a total of 24 parents drawn from two research sites in England: one was predominantly urban, the other was rural. Since the purpose of qualitative research is to identify the issues that are important to participants, rather than to make statistical generalisations about the wider population, the size of the sample is acceptable for qualitative research. However, there were a number of characteristics of this sample which need to be taken into account when considering the findings. First, the majority of the parents involved in the study had family members living close by who were able to offer them practical support with parenting. It seems unlikely that this is typical of patients with IBD throughout the UK, particularly those living in areas where populations are more transient. As a result, it may be that this study overestimates the extent to which parents with IBD receive help from family

members and underestimates the help needed from outside agencies. Secondly, only five out of the 24 participants were male, making it difficult to draw conclusions about fathers from the study, particularly as it seems likely that the men who took part in this study may have experienced more severe symptoms during their life time than many with IBD. Three of the five fathers had an ileostomy and only two of the fathers were employed (one full-time, one part-time). In the NACC survey, 60.8 per cent of men were employed and unemployment was associated with severe disease (Walters, 2000).

A second limitation is that, while the study identified positive and negative effects IBD may have on parents and their children, we are unable to draw conclusions about the size or distribution of these effects in the wider population of parents with IBD. Collection of such data requires the administration of measures to quantify the scale of people's experiences. As explained previously, at the outset of the study we were not in a position to carry out such work since there was no previous research to guide our choice of measures. Quantifying the extent to which the issues identified by parents in this study are of concern to the wider population of parents with IBD is the next task for researchers investigating this area.

Turning next to the methods employed, our intention with this study was to hold focus groups for parents since this would give participants a chance to share experiences and formulate ideas about how services might best support parents. In practice, it proved difficult for parents to attend the groups because of family commitments and poor health. A few parents who did come to a focus group spoke of how nervous they had been prior to attending because of concerns about toilet facilities and whether they would be able to come and go from toilets as they pleased. Such comments in themselves gave us an insight into the difficulties some parents experienced in their daily lives. In order to ensure we did not exclude parents who could not attend a focus group from the study, we decided to offer to interview people on an individual basis. Carrying out this series of interviews added considerably to the time it took to complete the study and, in retrospect, it might have been more realistic to have planned to interview all parents. However, there was one major advantage to running the focus groups: many of the parents who attended spoke of how much they had enjoyed and learnt from the experience, with few having had the chance to meet other parents with IBD before.

Research into the impact of parental chronic illness has been heavily criticised for being negatively biased, searching for problems in both parents and their children. We decided to overcome this problem by asking parents to draw up a time line charting the effects IBD had on them as parents and on their children. By giving parents different colour pens with which to note positive and negative experiences we were able to get an overview of experiences. In

addition, it ensured that parents thought back retrospectively over the life of their child, charting the changes for both them and their child. We would recommend the use of such non-verbal techniques to other researchers.

4.3 DISCUSSION OF THE FINDINGS

Overall the findings indicate that IBD has the potential to create a number of difficulties and few benefits for parents. Such findings are in keeping with the few previous studies carried out with parents with other chronic illnesses (le Gallez, 1993; Thorne, 1990; Allaire, 1988). The difficulties parents experienced related both to parental responsibilities (caring for the child; associated domestic responsibilities, such as shopping; taking the child to and from school; playing with the child; and organising social activities) and to the emotions associated with being a parent and having IBD. The main positive effect on parenting was developing a closer relationship with the child, but this was reported by a minority parents.

There was considerable variability in the difficulties experienced by parents as a result of having IBD. Unlike previous studies involving parents with a chronic illness, this study examined reasons for this variability and found that four factors seemed to influence experiences. First, since the difficulties in carrying out parenting responsibilities were attributed to symptoms such as incontinence, pain, tiredness and nausea, *severity of symptoms* played a major role in determining the level of difficulty experienced. However, it was not just the symptoms which caused difficulties for patients, *anxiety about symptoms* also influenced experiences. Parents said that even when they were relatively well, fear of incontinence/diarrhoea was enough to disrupt family life, preventing them from planning events with their children and from going places where there was potential for embarrassment. This finding fits with the family systems-illness model (Rolland, 1999), which proposes that illness can incapacitate an individual through the social stigma associated with the condition, and that unpredictable illnesses are a significant source of strain on families, making it difficult to plan for the future. It also concurs with the emphasis given in the stress and coping model to the individual's appraisal of a stressor (for example, Lazarus, 1999).

Moving on to consider the third factor which influenced the impact of IBD on parents - *whether the parent was a mother or father* - overall mothers reported more negative effects than fathers. This difference partly reflected the fact that fathers were less involved in practical parenting tasks. In addition, while fathers did speak of worries about their child's health due the hereditary nature of IBD, only mothers spoke about feelings of guilt due to the restrictions the condition placed on family life, not being able to attend school events, or not being as maternal as they would have liked. Such differences between mothers and fathers are in keeping with

theories of stress and coping, which hypothesize that in order for a situation to be stressful, it first has to be appraised as 'relevant to one's values, goal commitments, beliefs about the self and world, and situational intentions' (Lazarus, 1999:75). If parenting is not as central to fathers' views of themselves as it is to mothers, then it follows that difficulties in parenting are less likely to be appraised as a source of stress. As noted before, we do need to be cautious about drawing conclusions about the experiences of fathers from findings based on such a small and possibly unrepresentative sample. Clearly more research is needed on the experiences of chronic illness in fathers since none of the previous studies of parents' experiences have involved fathers (le Gallez, 1993; Thorne, 1990; Allaire 1988).

Fourthly, differences in the effect IBD had on parents varied according to *the age of the child*, reflecting the changing role of parents as children develop. Infants and pre-school children are highly dependent on parents and require intensive care and attention. Difficulties experienced by parents reflected this, including problems caring for the child (feeding, changing nappies, dressing, bathing and so on); playing with the child; taking the child out of the house, either to go shopping or for social purposes; and dealing with crying or misbehaviour. Once children entered school, taking the child out and dealing with misbehaviour continued to be an issue for parents. However, a number of new issues also emerged, such as getting the child to and from school, and attending school events. At this age, the child also wanted to spend more time out of the home and with friends, and organising this was a major issue for parents. As children grew older and became more independent, they could take themselves to and from school and did not have to rely as much on parents to organise their social life. They were also better able to care for themselves, for example making snacks, going to the corner shop to buy food, switching on washing machines. As a result, the negative effects of IBD experienced by parents were reduced. The remaining issues for parents of secondary school children were difficulty attending special events, such as school prize giving, concerts, and sports days; going on holidays; and, for a few, embarrassment about incontinence increased as the child got older. These findings highlight that the difficulties encountered by parents are not simply a product of their condition, but the result of a transaction between the parent and the child. Again, they are in keeping with the family systems-illness model (Rolland, 1999), which predicts that parents who have a chronic illness will experience most strain during the early years, when the care giving must be balanced between the child and the ill parent. It may be reassuring for parents to know about such age related differences since they suggest that parenting will get easier as the child gets older, and particularly when s/he reaches secondary school age.

Parents found the task of identifying effects they had noticed in their children as a result of IBD quite difficult. Part of this difficulty seemed to be around deciding whether a particular

behaviour could really be attributed to IBD or was caused by other factors. Overall, most described a mixture of both positive and negative effects in their children. The most frequently mentioned positive effect was the child being caring towards others, particularly those who were unwell, which is in keeping with previous research with parents (le Gallez, 1993; Thorne, 1990; and Allaire 1988). It is important to note that in this study children were not acting as carers for their parents, with only one parent mentioning children taking on domestic responsibilities to any extent. A few parents spoke of their children being more independent or mature than their peer group. Other positive effects were: developing closer relationships with family members, including the ill parent, than they might otherwise have done; and being able to recognise the signs of IBD.

In terms of negative effects, parents spoke about the effects IBD had on their child's everyday life, with the most frequently mentioned difficulty being restrictions on children's social activities. They also described the way in which their children reacted to them having IBD. The most frequently reported negative reaction was anxiety or worry, and a few spoke of children getting angry or frustrated. However, overall it seemed that these reactions were in response to specific incidents and were fairly transient in nature. For example, anxiety was reported most frequently in response to parents being hospitalised, and anger usually occurred when children were unable to do what they wanted because of the parent's illness. These findings are in line with studies examining children's adjustment to other parental chronic illnesses, which find that any psychosocial problems are not in the clinical range of severity. However, previous research comparing parents' reports with children's self reports has found that parents tend to underestimate the difficulties their children experience (Korneluk and Lee, 1998). Therefore it is possible the findings from this study underestimate the difficulties experienced by children of parents with IBD, and it is important that future research gathers the views of children themselves.

In general, negative reactions by children were reported to decrease with age, as the child's understanding of the parent's illness increased. In this study, there was no clear difference in the effects mothers and fathers noticed in their children. While fathers with IBD may experience fewer problems with child care than mothers, this lack of difference may be explained by the fact that from the child's perspective there may be similar consequences: family activities may be limited; the father may have hospital treatment; and fathers are as likely as mothers to be irritable as a result of their IBD. Further research with a larger, more representative sample of mothers and fathers is needed before we can be certain as to whether the gender of the parent with IBD makes a difference to children's adjustment.

Parents spoke of using a wide range of strategies to cope with any difficulties they experienced. It was clear that many were avoiding a whole range of situations such as shopping trips, days out with the family or other parents, school events, and travel of any distance, in order to avoid suffering embarrassment due to incontinence or diarrhoea. Therefore, it seemed that one of parents' strategies for coping with incontinence and diarrhoea was in turn creating difficulties for them as parents and for their children.

Aside from avoidance, by far the most common way of coping was through social support and a range of practical strategies. Social support consisted mostly of parents turning to partners and close family to help them with parenting tasks. Parents were much less keen to turn to friends and neighbours for support, fearing that this would be too much to burden them with, replicating findings in a previous study of mothers with arthritis (Allaire, 1988). The extent to which parents were relying on social support in order to cope is significant since it highlights the vulnerability of parents who do not have such support.

Practical strategies were also commonly used. Many were focussed on preventing problems from arising by controlling symptoms; having an ileostomy; family planning; and taking action to alleviate stress on the well parent and the child. Some of these strategies require understanding and input from the clinicians from whom the parent receives medical care. Other practical strategies focussed on dealing with difficulties frequently experienced, including getting children to and from school; the child's anxiety and misbehaviour; and incontinence.

It is worth acknowledging that, while being a parent could be difficult for parents with IBD, having children helped some parents to cope with IBD in general. Children could be a source of support in dealing with IBD, helping out and comforting parents when unwell, and encouraging them to do things they found difficult to manage. Many parents also spoke of being able to get easier access to toilets because they had a young child, and they were able to blame embarrassing smells on babies.

Since there is speculation in the literature that it is beneficial to talk to children about the parent's illness, we specifically asked parents for their views on this issue. Unlike Allaire's (1988) research with mothers with arthritis in which participants recommended that parents talk to their children about their condition, a few parents in this study were unsure whether this was appropriate, expressing concerns about worrying their child. This is an area where it would be useful to have some further research so that parents can be advised as to whether or not it is best to talk to their child. However, parents reported that children differed in how much they

wanted to now, suggesting that it may be impossible to be prescriptive about what children are told.

4.4 IMPLICATIONS FOR PRACTICE

Many parents had already received valuable support from health and education services. Parents spoke appreciatively about health staff who: they could talk to about their condition; understood the family situation; helped them prepare for important events in their life, such as holidays and school outings; were easy to contact; respected their views on altering medication or having treatment; put them in touch with other parents who had IBD; and supported mothers before and after the birth of their child. In relation to education services, some school staff were found to have been extremely helpful towards parents of younger children who had difficulty getting their child to and from school.

Nevertheless, it was clear from the findings that there are areas where support to parents and children could be improved. A number of suggestions were made about ways in which patients with IBD in general might be better supported. These included: better public awareness about the nature of IBD; better understanding of IBD by generic health care staff; specialist wards for patients with IBD; reductions in prescriptions costs; and access to disabled parking. Many of these suggestions are issues which NACC is already working hard to resolve and the findings reinforce the importance of work in this area.

Turning specifically to support for parents, it was clear from participants' responses that there is no one group of professionals who can take sole responsibility for supporting parents with IBD: parents specified that assistance was needed from health, education, social services, housing, and voluntary organisations such as NACC. The findings suggest that support from health professionals for IBD patients in their parenting role was provided on an ad hoc basis, depending on the individual personality and interests of staff. The few parents who had approached school staff had found them very helpful, but embarrassment had prevented many parents from disclosing their condition to others, such as school staff. Support from other services seemed to be largely absent, although it must be acknowledged that few parents had approached services for assistance. In the remainder of this section, we draw on all the data gathered from parents, including both their experiences as a parent and their messages to service providers, to discuss the implications of the findings for practice. This discussion is split into two parts: support for parents and support for children.

4.4.1 Support for parents

Given parents' description of the difficulties they encounter, and the cause of these difficulties,

it would seem that services can support parents with IBD at two levels: by helping to prevent difficulties from developing in the first place; and by offering support when difficulties do emerge.

Support to prevent difficulties developing

- **Support in dealing with symptoms**

Since parents linked the difficulties they experienced to the symptoms of the condition, it may be possible to prevent difficulties from developing by taking action in these areas. Needless to say, health professionals already work hard at alleviating patients' symptoms and improving their quality of life. However, findings from this study suggest that controlling symptoms may be complicated by parenting responsibilities. Parents spoke of how much more difficult it is to recover from flare-ups and surgery if there is little opportunity to rest when at home, and some requested facilities to convalesce away from family. Arranging such support suggests a need for health professionals to work with other agencies, such as social services, who may be able to provide respite services or domiciliary help. Clearly this level of support will not be needed by the majority of parents with IBD, but it could be very valuable to those who have particular difficulty getting the rest they need because they have young children and little family support.

Parents may also need some psychological support in managing symptoms. For some parents who took part in this study, the fear of incontinence and diarrhoea was enough to prevent them from taking part in everyday parenting activities, such as taking their child out to play or going to a school event. This finding has important implications for practitioners since it means that reducing patients' symptoms may not be sufficient to improve their quality of life.

Having an ileostomy is one way of controlling symptoms that may be considered by some patients. It was clear from this study that people who had an ileostomy had found it very beneficial in terms of coping with family life. However, it was also apparent that for many people this was a very difficult decision to take, and it is not an appropriate option for all patients. The study has highlighted that parents considering having an ileostomy find it extremely helpful to talk to other parents who have one.

- **Consideration of family circumstances when arranging hospital treatment**

Going into hospital was reported to be a source of anxiety for patients with young children, particularly if they had difficulty organising child care. Given that it is currently unclear whether stress exacerbates IBD, it would seem wise to consider family circumstances when organising treatment for patients. If hospitalisation is particularly problematic for patients, then it may be worth considering alternative arrangements such as offering treatment at home,

or rescheduling to a more convenient time where possible.

- **Support with family planning**

One way of preventing difficulties reported by parents in this study was through family planning, either leaving it a number of years between having children, or sometimes deciding to limit the number of children they had. Part of helping parents to manage their condition includes helping them to make such decisions. Parents in this study requested that patients be provided with information on the effects IBD on pregnancy and family life. Both health professionals and NACC could play a role in providing such information.

- **The discussion of worries about the hereditary nature of IBD**

Another area where parents clearly need accurate information is in relation to the hereditary nature of the condition. The possibility that their child might develop IBD was a worry mentioned by a number of parents, both for themselves and a concern they noticed in their children. Most parents were aware that there was some genetic basis to the condition. However, they had no information about the likelihood of their children developing the condition. Some of parents' worry about children developing IBD could be alleviated if families are given information about the level of risk.

Support for parents experiencing difficulties with their parenting role

We now move on to consider the role that services can play in helping parents who are experiencing difficulties. First, in order to assist this group of parents, practitioners need to recognise when patients are experiencing problems. A number of mothers in this study said they did not talk to anyone when they were experiencing difficulties. Those who had received support from midwives and health visitors had only done so because the professional had noticed they needed help. Therefore, it seems that professionals need to be proactive in checking whether parents want assistance. It has been suggested that professionals involved with chronically ill patients are reluctant to discuss parenting issues for fear of distressing their patient (Altschuler and Dale,1999). Our experience in carrying out this study has been that many people with IBD, particularly mothers, have welcomed the opportunity to discuss how they balance the demands of being a parent with having IBD and would be open to talking about such issues with health professionals.

Given that patients are most frequently in contact with GPs, gastroenterologists and specialist nurses in gastroenterology clinics, these are the most obvious groups of professionals to take on this role. This study suggests that those most likely to experience difficulties are mothers of young children who have little family support. In addition, since a proportion of mothers

reported experiencing flare-ups after the birth of their child, professionals should be especially vigilant towards mothers during this time. This group of patients are also likely to be in touch with midwives and health visitors, so they too can play a role in offering support.

One of the first steps may be to explore with parents what resources they have available to them for managing the situation, encouraging them to make use of family support and discuss their situation with the child's school. Talking to school staff may not be easy for parents if they do not generally discuss their condition with others, and they may need help in thinking about how they will handle this. However, parents in this study who had taken such a step spoke very positively about the benefits of doing so.

Securing help from partners depends on them understanding and accepting IBD and its impact on family life, and as parents in this study pointed out, it cannot be assumed partners will respond in this way. Parents in this study felt that support for partners in coping with IBD was a gap in current service provision, suggesting that support groups specifically for partners should be set up. However, we do not know whether partners themselves want such a service. Another option might be for health professionals to encourage partners to attend clinic appointments so that they are involved in discussions about the management of the condition and implications for family life. Offering such support obviously has implications for practitioners' time, and it may be worth considering whether this role can be undertaken by specialist nurses.

If family support is limited, parents may want to consider accessing help from services. However, such help may not easily be obtained. A recent Social Services Inspectorate (SSI) report on support for disabled adults in their parenting role (Goodinge, 2000) notes that there is considerable variation between councils in the number and type of services provided to disabled parents. The report found that access to services was hindered by the fact that disabled parents fall between adult and child services: adult services did not recognise the potential impact of being a parent; for children's services parental disability was not seen as a factor in assessing a child as 'in need'. As a result, practitioners rarely looked at the needs of the whole family and how to support parents in their parenting role. Nevertheless, a wide range of services was being provided by various voluntary, independent and statutory services. These included domiciliary care, equipment, child day care, adult respite, counselling, parenting courses, transport, and adult day care. While some of these services might not be necessary for parents with IBD, many do fit with the kinds of support parents felt were needed, such as getting children to and from school, shopping, housework, and cooking. They also include services which might help parents recover from flare-ups or surgery, the importance of which

has already been discussed. It was notable that none of the parents who took part in this study were accessing any of these services.

Even when such services are available in the areas in which they live, there are two reasons why parents with IBD may have difficulty accessing them. First, parents with IBD are unlikely to be in contact with services for disabled people. They are not generally recognised as disabled by service providers, nor do they necessarily perceive themselves as disabled. In addition, many of the parents in this study said that, because of the embarrassing nature of their symptoms, they only discussed their condition with members of their family. It therefore seems unlikely that parents with IBD will seek out support from services if it means having to describe their difficulties in detail in order to justify their need for help. A second difficulty for parents in accessing such mainstream services is the fluctuating nature of IBD, making it impossible to predict when support will be needed.

It is important that further work is carried out to identify and make parents aware of the services which are already in place, which they might be entitled to access. Service providers also need to be made aware of the difficulties parents with IBD may experience. It is important that local education authorities are included in any awareness raising exercise since findings from this study suggest getting children to and from school was one of the most common difficulties for parents. This is an area already singled out as needing improvement in the SSI report on services to support disabled parents.

Since the fluctuating nature of IBD may make it inappropriate for parents to access services which are provided on a regular basis, parents who took part in the study suggested that there should be some form of crisis support service. They felt this service should be targeted at parents most likely to run into significant difficulties with parenting due to having severe symptoms and lack of family support. One of the difficulties in setting up such a service is that it may not be seen as a priority because of the low numbers of parents with IBD in any one area likely to use it. However, a needs assessment may indicate that such a service is needed to support parents with a range of chronic conditions.

Since this study was carried out, NACC have launched a new support service - the NACC-in-Contact Support Line - which offers confidential, emotional support over the telephone provided by trained volunteers who have personal experience of IBD. Our evidence suggests that this will be welcomed by parents, particularly if issues such as support after the birth of a child, dealing with difficulties in caring for a child, and support for partners can be addressed.

4.4.2 Support for children

Turning to the implications of the findings in relation to support for children, first it is clear that by supporting parents services will in turn be supporting their children. Based on the findings from this study, there does not seem to be any great need for specialist interventions to support children themselves. However, the findings from this study are preliminary and we cannot be certain at this stage of the implications of parental IBD for children's adjustment. What we can say is that parents would find it useful to have a book to help them explain IBD to their children.

In particular, it would be useful if this book covered aspects of IBD which parents find difficult to explain (ileostomies, being too tired to do things, equipment in hospital, why you are not allowed to eat while on a drip, and why you need to use a toilet so much). Parents would also welcome the opportunity for their children to meet with others in a similar situation. Given that it is important to parents that this happen in a relaxed and informal way, so that children do not feel forced into talking to other children, it would seem that NACC is in the ideal position to facilitate such meetings. This could be done through organising social events for families, which would fit with parents request that NACC take a more holistic view of the condition and develop a more welcoming image for families.

4.4.3 Conclusions

IBD has the potential to create difficulties for parents, both in carrying out their parenting tasks and emotionally. However, the support needed by this group of parents is somewhat hidden: health services focus on treatment of the condition; services usually involved in supporting parents are unlikely to recognise the needs of patients with IBD; and parents themselves report not discussing their difficulties with others, tending instead to 'keep it within the family'. Parents would welcome professionals and voluntary organisations already involved with patients with IBD taking a more holistic approach to IBD, considering parenting responsibilities when offering treatment, information and support. Services involved in supporting parents need to be made aware of the implications of IBD for families.

4.5 DISSEMINATION PLAN

With the agreement of NACC, this report will be made available through the Social Policy Research Unit Information Office, with details listed on the Unit website. We will also produce a summary report which will be published in the SPRU 'Research Works' series. Research Works publications are summaries on four sides of A4 in lay language. Three hundred copies will be produced in attractive format and distributed free of charge to research participants, service providers, policy makers, and other relevant parties. The full text of every Research Works is also placed on the SPRU website.

A report will be produced for the NACC newsletter and a paper will be written for a relevant academic journal. An abstract has been submitted and accepted for presentation at the British Psychological Society Annual Conference in March 2001.

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APPENDIX ONE

Information Leaflet

UNDERSTANDING THE IMPACT OF INFLAMMATORY BOWEL DISEASE ON PARENTS AND THEIR CHILDREN

A Research Study Funded by the National Association for Colitis and Crohns Disease

ORIGINS OF THE RESEARCH

In 1995 the National Association for Colitis and Crohns Disease (NACC) carried out a survey of almost 2,500 of their members. The survey revealed that 42 per cent of those who responded were worried about the effects of the condition on members of their family, other than their partners. A number of respondents specifically mentioned difficulties in caring for their children due to the condition. As a result of these findings, NACC feel it is important to know more about the situation of parents who have inflammatory bowel disease (IBD).

AIM OF THE RESEARCH

The aim of the research is to investigate:

- ▶ Parents' views on the effects of IBD upon their children.
- ▶ How they deal with the effects of IBD on family life.
- ▶ What type of support they need to help them manage being a parent.

WHY IS THE RESEARCH IMPORTANT?

The findings from this research can help educate both professionals and families about life for parents who have IBD. Understanding the problems families *may* face, and how parents overcome them, can help others to prepare for and cope with similar difficulties, and will help professionals to provide more appropriate information and support.

WHO IS CARRYING OUT THE RESEARCH

Two researchers from the Social Policy Research Unit (SPRU), University of York, are carrying out the study. Our names are Tricia Sloper and Suzanne Mukherjee. We have both worked in research for many years and have a lot of experience in carrying out similar research.

SPRU has a long established and successful record of social science research on disability and chronic illness and family life, as well as expertise in consulting children, parents and professionals. If you are interested to know more about us and have access to the internet, you might like to take a look at our web site: <http://www.york.ac.uk/inst/spru/>

WHO SHOULD TAKE PART?

Anyone who is the parent of a child aged between 5 and 16 years of age and has IBD is invited to take part in the study. Parents will have different experiences in managing IBD. Some of them will be positive and some of them will be negative. We are interested in hearing about all these experiences.

WHAT DOES TAKING PART INVOLVE?

If you decide to take part in the research, we would invite you come to a meeting to discuss what it is like to have IBD and be a parent. The discussion group will last two and half hours and will be held in the centre of York/Scarborough. Up to 10 parents will be invited to each meeting. We will arrange the time of the discussion group after talking to all parents taking part about what is convenient for them. We will pay any travel expenses incurred as a result of attending a meeting.

We are hoping to hold separate discussion groups for parents of children aged 5-11 years and 12-16 years. If you have children in both age ranges you can choose which discussion group you prefer to attend. You are welcome to bring your husband/wife/ partner/friend with you to the meeting.

If you would like take part in the research but are unable to come along to a meeting, please get in touch with us and we will try to come to an alternative arrangement.

WHAT WILL HAPPEN TO THE INFORMATION YOU PROVIDE?

All the information you pass on to the researchers during the course of the study will be treated as confidential. As long as everyone in the group agrees, we will tape record the discussion, so that we have a record of all the issues discussed and everyone's views. This information will be used to write a report for NACC. However, the names of people who have taken part in the research will not appear in the report or in any other articles written about the project. All those who take part in the research will be sent a summary of the final report. This summary will also be placed on the SPRU website, as well as being passed on to NACC and the British Society of Gastroenterology for wider distribution. In addition, an article will be written for the NACC newsletter.

THE TIMETABLE

We plan to hold discussion meetings with parents during June and July 2000. The final report on the research will be completed by the beginning of October 2000. Participants in the study will receive a summary of the research findings around the same time.

WHAT HAPPENS NEXT

If you decide you would like to consider taking part in the study or would like more information, then you can discuss this with one of us at the clinic, or fill in the form saying 'yes' and return it to us in the pre-paid envelop provided. In this case, one of us will contact you to discuss the project further when we receive the form. If you then decide you are willing to take part in the study, we will contact you to make arrangements about the group meetings.

If you do decide to take part, you are still free to withdraw at any time without giving a reason. Whether you take part in the project or not will not affect any of the services you receive from health or any other professionals.

APPENDIX TWO

Consent Form

**UNDERSTANDING THE IMPACT OF INFLAMMATORY BOWEL
DISEASE ON PARENTS AND THEIR CHILDREN**

CONSENT FORM

Please tick the boxes below as appropriate

- I am willing to be interviewed about the impact of inflammatory bowel disease on parents and their children

- I understand that I am free to withdraw from the research at any time and that I do not have to give a reason for deciding to withdraw.

- I am aware that the information collected during the interview will be used to write up a report on the project, as well as articles for journals and newsletters.

- I understand that information collected during the course of the research project will be treated as confidential. This means that my name, or any other information that could identify me, will not be included in anything written as a result of the research.

Signature:

Date:

APPENDIX THREE

Background Questionnaire

**Understanding the impact of inflammatory bowel disease on
parents and their children**

BACKGROUND INFORMATION

We would be very grateful if you completed this form, providing us with some background information on your family circumstances and your health. This information will give an overview of the different experiences of people who take part in the research project. All the information provided during the course of the project will be treated as confidential.

Name Date of birth

Please tick the boxes below as appropriate.

How did you first find out about the project ?

- Through meeting a researcher in the hospital
- Through receiving a letter from you consultant
- Through the local NACC group
- Other (please specify)

Are you a member of the National Association of Colitis and Crohn's Disease (NACC) ?

Yes No

FAMILY CIRCUMSTANCES

Please provide some basic information on the age and sex of your children by completing the box below.

Child	Age	Sex	Is this child living at home?
1			
2			
3			
4			
5			

Do you live with a partner/spouse?

No

Yes

Are you working at present ?

No

Yes, part-time

Yes, full-time

If yes, please state occupation

ILLNESS EXPERIENCE

How long have you had symptoms of inflammatory bowel disease?

How long is it since you were first diagnosed?

Please state your diagnosis

Ulcerative colitis

Crohn's disease

Other (please specify)

Have you had any surgery as a result of inflammatory bowel disease?

Yes

No

If yes, please describe:

.....

.....

.....

.....

.....

APPENDIX FOUR

Short Inflammatory Bowel Disease Questionnaire

The short inflammatory bowel disease questionnaire (SIBDQ)

This questionnaire is designed to find out how you have been feeling during the last 2 weeks. You will be asked about symptoms you have been having as a result of your inflammatory bowel disease, the way you have been feeling in general, and how your mood has been. *All the information you provide will be treated as confidential.*

Name Date

1. How often has the feeling of fatigue or being tired and worn out been a problem for you during the last 2 weeks? Please indicate how often the feeling of fatigue or tiredness has been a problem for you during the last 2 weeks by picking one option from:

- a) All of the time
- b) Most of the time
- c) A good bit of the time
- d) Some of the time
- e) A little of the time
- f) Hardly any of the time
- g) None of the time

2. How often during the last 2 weeks have you had to delay or cancel a social engagement because of your bowel problem? Please choose an option from:

- a) All of the time
- b) Most of the time
- c) A good bit of the time
- d) Some of the time
- e) A little of the time
- f) Hardly any of the time
- g) None of the time

3. How much difficulty have you had, as a result of your bowel problems, doing leisure or sports activities you would have liked to have done during the last 2 weeks? Please choose an option from:

9. How much of the time during the last 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels were empty? Please choose an option from:

- a) All of the time
- b) Most of the time
- c) A good bit of the time
- d) Some of the time
- e) A little of the time
- f) Hardly any of the time
- g) None of the time

10. How much of the time during the last 2 weeks have you felt angry as a result of your bowel problem? Please choose an option from:

- a) All of the time
- b) Most of the time
- c) A good bit of the time
- d) Some of the time
- e) A little of the time
- f) Hardly any of the time
- g) None of the time

Thank you very much for completing this questionnaire.

We would be grateful if you could return it in the pre-paid envelope provided

APPENDIX FIVE

Topic Guide

FOCUS GROUP TOPIC GUIDE

PRELIMINARIES

Consent form

Expenses

Questionnaire - 'Background Information'

WELCOME AND INTRODUCTIONS

(Researcher 1)

Thanks for coming to the meeting

Introduce the researchers

Explain the purpose of the research study

As you are aware, the purpose of the study you have agreed to take part in is to understand the impact that inflammatory bowel disease has on parents and their children. One of the reasons we are carrying out this work is that a survey carried out by NACC in 1995 found that quite a large proportion of people were worried about the effects of their condition on members of their family. NACC have funded us to find out more about how IBD is affecting parents and their children. Findings from this type of research can help to educate professionals about life for parents who have IBD and ensure that they provide more appropriate support. It may also help people with IBD who are considering having children, by giving them information on what to expect.

Over the next few weeks we hope to speak with up to 40 parents. Everyone who takes part will have been contacted either through meeting us at a clinic, through receiving a letter from their consultant, or through NACC.

The plan for meeting

During the meeting, we will talk about:

- the effect inflammatory bowel disease (IBD) has on everyday life
- how IBD affects you as a parent
- the effects you have noticed in your children
- ways of dealing with difficulties
- the support parents with IBD would like from services

Throughout this evening we would like to get an overview of your experiences in being a parent with IBD; in other words we want to hear both about any benefits and any difficulties you have experienced.

Tape recording

As I mentioned in the letter you received about the meeting, we will tape record the discussion.

Is that OK? All the tapes are given a code so that they remain confidential - we do not write people's names on the tape. The tapes will go to a transcriber, but aside from this person, the research team are the only people who will have access to this tape. At the end of the study all the tapes will be wiped. The data from all the meetings will be analysed and written up as a general summary. Your names will not be included in anything written as a result of the project.

During the meeting, we will ask you to write a few things down. We would like to take in all this written material at the end of the meeting.

Ground rules

When we run meetings like this we usually find it quite useful to have a few ground rules.

These are (refer to poster on wall):

- Everyone should have a chance to speak
- Everything discussed is confidential to the group
- We will finish the meeting at the time agreed

Does anyone want to add anything to this, or change it in any way?

House keeping

Please feel free to help your self to drinks.

Also to go in and out of the meeting as you wish.

Introductions

We are going to spend the next 10 minutes giving you a chance to introduce yourself. Can I ask you to introduce yourself and just say a sentence or two about your family and your health.

GENERAL QUESTIONS ABOUT IBD

(Researcher 1)

What we would like to do now is begin the discussion by asking you to think generally about the effects of your condition on everyday life. To help you do this, we are going to give you a couple of minutes to think about this on your own. Can you take a slip of paper and write down the three main ways in which IBD affects your everyday life. Once you have done, this we will come back together and have a short discussion about it.

HOW IBD AFFECTS YOU AS A PARENT

(Researcher 2)

Now moving on to focus in on one aspect of people's lives - being a parent. We would like you to think about both the positive and negative ways in which IBD has affected you as a parent. To help you do this, we would like you to use this time line (see Appendix 6). Ignore the bottom half of the page for now, and on the top half write how IBD has affected you as a parent during the different phases of your child's life: when your child was of pre school age, primary

school age, and secondary school. Those of you with younger children will only be able to complete part of the time line. We would like you to use a red pen to write about positive effects and black pen for negative effects. We will leave you for about 10 minutes to work on your time line and then we will come back together as a group to discuss it.

THE EFFECTS YOU HAVE NOTICED IN YOUR CHILDREN

(Researcher 2)

Now complete the bottom half of the time line in the same way as before, using red and black pens, this time thinking about effects you have noticed in your children.

WAYS OF DEALING WITH DIFFICULTIES

(Researcher 1)

What we would like to do now is find out about how you have dealt with any difficulties you have encountered. To help you do this, we would like you to go back to your chart and look at the difficulties you or your child have experienced. Then write in green pen anything you have done which has helped overcome these difficulties. We will come back together in 10 minutes and discuss your ideas.

(Researcher 2 to write up on flip chart things that have helped)

Probe> Is there any thing you have tried which has very definitely not helped ?

TALKING TO CHILDREN

(Researcher 1)

We are particularly interested in whether people find it useful to talk to their children about IBD.

Probe >What aspects of IBD do you discuss with your children?

Probe> Have you found it helpful or unhelpful to talk?

(Add ideas to be added to list of coping strategies on flip chart)

THE SUPPORT PARENTS WITH IBD WOULD LIKE FROM SERVICES

(Researcher 2)

Have you any messages for people providing services.

- about support for parents
- about support for children

By services we mean health, education, social services or voluntary organisations.

CLOSURE
(Researcher 1)

Thank you

What happens next

- report written in the Autumn
- you will get a summary of this report
- an article will be written for the NACC newsletter

APPENDIX SIX

Time Line

THE TIME LINE

How IBD has affected you as a parent

.....PRE SCHOOL.....

0-4 years

.....PRIMARY SCHOOL.....

5-10 years

.....SECONDARY SCHOOL.....

11-16 years

The effects you have noticed in your children